Longitudinal measurement of the older patient's vision-related quality of life

van Nispen, R.M.A.

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Ruth M.A. van Nispen

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The studies in this thesis were performed at the Department of ophthalmology and the EMGO Institute for Health and Care Research at the VU University Medical Center Amsterdam, the Netherlands

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door

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geboren te Vlissingen

promotoren:	prof.dr. G.H.M.B. van Rens
	prof.dr. P.J. Ringens
copromotor:	dr. D.L. Knol

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Preface

In conversations I have had with visually impaired older patients, the detrimental impact of having a visual impairment was expressed by statements such as: "In the past two years my vision has gone down rapidly. Now I'm afraid to go outside because I don't see the traffic very well"; "I can't read my newspaper or novels anymore"; or, "I'm embarrassed when I don't recognize acquaintances who don't know about my visual impairment. I know it's irrational, but I worry that they might think I'm ignoring them". Although these remarks contribute to our understanding of how it is to live with a visual impairment, they do not allow for a thorough and systematic evaluation of a person's quality of life.

The main objective of the work in this thesis is to assess the quality of life of visually impaired older patients. Consequently, special attention is paid to the best method to use when assessing the quality of life of these particular patients.

In the various chapters, several topics are encountered that are covered by the title *Longitudinal Measurement of the Older Patient's Vision-related Quality of Life*. First of all, the word 'Longitudinal' refers to the observational study performed to investigate the long-term outcomes of low-vision rehabilitation. 'Measurement' refers to the variables investigated, the questionnaires used, and the measurement techniques and models from item response theory applied. The 'Older' visually impaired patients, who were referred from ophthalmology departments to low-vision rehabilitation services, is the population that is subject to most chapters in this thesis. Our investigations were not only related to vision, but also focused on the patient's general health and, more specifically, on co-morbidity and health-related quality of life. Finally, the term 'Vision-related quality of life' refers to the specific construct that was measured with the questionnaires. In addition, the psychometric quality of the vision-related quality of life questionnaires was investigated.

These topics are summarized in three main themes, which I will further introduce in Chapter 1:

1. Psychometric quality of vision-related quality of life questionnaires;
2. Longitudinal outcomes of low-vision rehabilitation;
3. Co-morbidity and health-related quality of life of older visually impaired patients.

Producing this thesis would not have been possible without the cooperation of all participants of the longitudinal study. Even after more than 4 years, many of them were still willing to complete the questionnaires again - by themselves or with help from others. For some of the visually impaired older patients this was quite a burden; nevertheless, they still managed and we are very thankful for that. I would like to gratefully acknowledge their input in this preface, because the information they provided will enable us to improve research strategies, ophthalmic care, and low-vision rehabilitation services for future patients.

Ruth van Nispen

CHAPTER 1

General introduction

Introduction

The main topics addressed in this thesis are: the psychometric quality of vision-related quality of life questionnaires; the longitudinal outcomes of low-vision rehabilitation; and co-morbidity and health-related quality of life of older visually impaired patients. Presented below is some general information about the prevalence of people with a visual impairment, the definition of low vision and blindness, and the eye conditions that mainly cause low vision or blindness in older patients.

Prevalence and def inition of low vision and blindness

In 1999, the Global Initiative for the Elimination of Avoidable Blindness, also known as "Vision 2020: the Right to Sight", was launched[1]. Since then many prevalence studies have been carried out or have been updated, with the aim to investigate the number of people from different parts of the world with (avoidable) blindness and low vision. The idea behind this World Health Organization (WHO) initiative is to eliminate avoidable blindness before the year 2020 by providing information, by screening and, for example, by more efficient cooperation between those involved in eye care[1,2].

In a meta-analysis on large population-based studies in the USA, the Caribbean, Australia and Western Europe, prevalence rates for visual impairment and blindness were reported to range from 0.6 to 2.1% and from 0.1 to 0.9%, respectively[3]. In prevalence studies, different definitions of visual impairment (which includes low vision and blindness) are used; this in turn limits comparability. However, in many studies, including the work in this thesis, the definition of the WHO is often reported. The WHO defines low vision as the best corrected visual acuity in the better eye ‹0.3 but ≥0.05, and/or visual field ‹20° around the fixation point; blindness is defined as the best corrected visual acuity in the better eye ‹0.05 and/or visual field ‹10° around the fixation point[4]. In the USA and Australia, low vision is defined as a best corrected visual acuity ‹0.5, which is primarily based on the required visual acuity for driving[5].

In developed countries, low vision and blindness are strongly associated with increasing age and the causes are determined by age[6]. Comparative studies have shown that the prevalence of visual impairment increases rapidly after the age of 65 and blindness after the age of 85 years[3,7]. In a prognostic study on the prevalence of low vision and blindness in the Netherlands between 2005 and 2020, the prevalence (when applying the WHO criteria) of visual impairment is expected to increase from 1.01 to 1.19% and blindness to increase from 0.40 to 0.43%[8]. Furthermore, it is estimated that the number of visually impaired adults in the Netherlands between 2005 and 2020 will increase by 18.7% from approximately 298,000 persons in 2005 to 354,000 persons in 2020. However, it should be noted that the latter estimation was based on visual acuity data assessed on the available correction, instead of the

best correction; this was done to be able to additionally estimate low vision caused by refractive errors. In 2020, approximately 94% of those visually impaired persons will be aged 50 years or older; a population increase in the Netherlands from 16.3 to 16.8 million persons was taken into account. In 2005, almost 80% of blind persons and almost 70% of persons with low vision was female. Others have reported similar differences in prevalence rates between males and females, also when corrected for age[3,9,10].

A limitation of prevalence studies is that they are often based on visual acuity data. Visual acuity is, however, only a part of visual disability, i.e. visual fields or contrast sensitivity are often not taken into account. Moreover, problems with visual field loss or contrast sensitivity may also only be a part of the disability experienced by patients. This makes it difficult to estimate the future demand for ophthalmic consultations or rehabilitation services[11].

Main causes of low vision and blindness

In industrialized countries, the most common causes of visual impairment are age-related macular degeneration, cataract, diabetic retinopathy and glaucoma. Age-related macular degeneration is an eye disease that gradually destroys central vision due to degeneration of the pigment epithelium and the photoreceptors in and around the macula lutea (also called the fovea), which is the center of the retina. The dry or atrophic form affects about 80% of macular degeneration patients. There is also a wet or exudative form in which new blood vessels start to grow which may cause leakage underneath the retina and finally lead to scarring of the retina. The wet form affects about 10% of the patients and another 10% has a mixture of both dry and wet macular degeneration. The fovea is responsible for being able to see details and for color vision. Macular degeneration makes it difficult to read or to do other visually demanding tasks because of a gradual loss of central vision, which progresses to severe low vision and blindness. Medical treatment is generally possible for the wet form but not for the dry or atrophic form of macular degeneration[12]; these latter patients mainly rely on low-vision rehabilitation.

Cataract in the older patient is an eye condition which blocks or diffuses light which enters the eye, caused by gradual opacification of the aging lens. Blurred vision, glare and haloes are early symptoms of cataract which worsen with the maturing of the cataract[13]. Extracting the cataract and implanting an artificial lens is beneficial for improving visual acuity in many cataract patients[14]; however, this is not always the case for patients with additional eye conditions[15].

Diabetic retinopathy is a complication of diabetes mellitus. Prolonged periods of high blood sugar levels damage the small blood vessels in the retina, which may cause hemorrhages and induce proliferative processes. This may lead to growth of

new or abnormal blood vessels, protein exudates on the retina, edema of the retina and possibly retinal detachment, leading to large 'blind spots' and eventually to severe vision loss or blindness[15].

In glaucoma part of the optic nerve is slowly destroyed by an increased pressure inside the eye. Other causes are poor blood supply to the vital optic nerve fibers, a weakness in the structure, or weak general health of the nerve fibers. Peripheral vision is usually affected, first causing a gradual visual field loss, as well as a decrease in contrast and light sensitivity. Treatment of glaucoma is aimed at stopping further damage to the optic nerve, for example by using medication that lowers eye pressure[16,17].

Finally, a refractive error is a common cause of vision loss; however, this is not considered to be an eye disease. A refractive error refers to a state in which the optical system of the non-accommodating eye fails to bring parallel rays of light to focus on the fovea. Myopia and hyperopia are states of refractive error in which the optical system of the eye brings parallel rays of light, anterior or posterior to the fovea, into focus causing a blurred vision. Refractive error can be relieved in most cases by spectacles, contact lenses, or refractive surgery[18].

In the study of Limburg (2007), age-related macular degeneration was reported to be the most common cause of blindness in the Netherlands in 2005, followed by cataract[8]. Others have reported similar findings[3,6,7,19]. Low vision was in most cases caused by cataract, refractive errors, macular degeneration or diabetic retinopathy. It was estimated that 56% of the causes of visual impairment could be treated (i.e. refractive errors and cataract) or possibly avoided by timely treatment and monitoring, i.e. about half of the glaucoma and diabetic retinopathy cases. Others reported similar results[6,9,18,20]. It was concluded that unless there is an increase in medical treatment options for macular degeneration by 2020, the distribution of eye conditions causing low vision or blindness will probably not alter[8]. Since a cure is basically lacking for persons with macular degeneration or for those with other causes of vision loss (except cataract), most of them will rely on low-vision rehabilitation as an important treatment option[20].

Psychometric quality of vision-related quality of life questionnaires

This section describes the concept of vision-related quality of life and the questionnaires used for its assessment. Information is also given about item response theory; some of these models were used to analyze the data from the questionnaires.

Vision-related quality of life questionnaires

The concept of quality of life is similar to the WHO definition of health as *"a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity"*[21]. Especially when a cure is not expected (as in many chronic diseases), it is nowadays widely accepted that any treatment choice should take the patient's quality of life (which reflects physical, psychological and social functioning) into account. Due to the irreversible nature of the eye conditions of visually impaired older patients, it is important to also take into account their quality of life, as well as offering the best available medical care. Apart from quality of life in general, the visually impaired patient's subjective perception in terms of vision-related quality of life is increasingly recognized as a meaningful representation of the patient's visual disability before and after medical treatment or rehabilitation[22,23].

Basically, there are two types of self-report health-related quality of life questionnaires: 1) generic questionnaires, such as the widely used SF-36 or the Euroqol (this thesis), intended for use both in general population surveys and in studies on patients with diverse health conditions; and 2) condition-specific questionnaires developed for use among specific patient populations[21], such as patients with macular degeneration or diabetic retinopathy. Vision-related quality of life questionnaires were developed because they enable to evaluate what is important to patients with respect to their vision. These questionnaires consist of items that largely reflect the disability suffered by the patient in daily life[24-28]. Most vision-related quality of life questionnaires have been developed and validated among patient populations in hospitals or low-vision rehabilitation centers[24,25,29]. Some questionnaires were designed to measure the outcome of a specific medical treatment, e.g. cataract surgery[30], or a rehabilitation program for persons with irreversible visual impairments, e.g. age-related macular degeneration[29].

In 2004, a systematic review was published by de Boer et al. which described more than 30 vision-related quality of life questionnaires[24]; they also reported criteria for assessing or choosing a questionnaire. Based on these criteria, the latter authors chose two questionnaires for use in their rehabilitation outcome study, namely the Low Vision Quality of Life Questionnaire (LVQOL) and the Vision-related quality of life Core Measure (VCM1)[31]. In this thesis, our study on longitudinal outcomes explored the same patient population as described by de Boer et al; the same two questionnaires were administered again, but this time with a mean (post-baseline) follow-up time of 4.4 years. Recently, Finger and colleagues (2008) reported on vision-related quality of life questionnaires specifically for patients with age-related macular degeneration[29]; we present some additional information following their publication.

Furthermore, in this thesis, three Dutch versions of vision-related quality of life questionnaires are evaluated with item response models: the VCM1, the LVQOL,

and the National Eye Institute–Visual Function Questionnaire–25 (NEI-VFQ-25). The VCM1 was originally developed by Frost et al.[32]. A large item pool was generated from interviews with patients, consultations with professionals, and the literature. The VCM1 was translated by Nijkamp and colleagues into Dutch[33]. The content of the VCM1 probably relates best to the psychological component of quality of life, because most of the items are about feelings and perceptions associated with visual disability.

The LVQOL was originally developed by Wolffsohn et al. to measure outcomes of low-vision rehabilitation services, particularly for patients with various eye conditions[34,35]. Previously developed questionnaires from the literature were used to generate a large item pool, which was further assessed by a multidisciplinary team and low vision patients to define the content of the questionnaire. De Boer et al. translated the LVQOL into Dutch[36]. The LVQOL has been translated and validated in Chinese[37] and in Thai[38]. In two separate studies, de Boer et al. validated the LVQOL and the VCM1 in the same visually impaired patient population[36,39]; the previous LVQOL studies used methods from classical test theory.

Some relevant studies on the psychometric properties of the NEI-VFQ-25 and other questionnaires were recently reported by Finger et al.[29]. The initial version of the NEI-VFQ was designed to capture the influence of vision on multiple dimensions of health-related quality of life[40,41]. Focus group discussions were conducted with persons with different eye conditions to generate an item pool, whilst defining the content of the questionnaire. However, because a shorter version was required for research and clinical settings, the NEI-VFQ-25 was developed[42]. This latter version has been investigated in patient samples with various eye conditions, and in low-vision rehabilitation and community samples. In addition to the Dutch validation study described in this thesis, the NEI-VFQ-25 has been translated and its psychometric quality investigated in other languages, including Japanese[43], Chinese[44], Turkish[45], Greek[46], French[47], Spanish[48], and others. The recent Greek and Chinese studies performed Rasch analyses to explore the psychometric properties of the NEI-VFQ-25[44,46]. In addition to the studies reported by Finger et al.[29], NEI-VFQ versions in the English language have been assessed either with classical test methods[49], Rasch analyses[25,50], or using the graded response model for rating scales[25].

Item response theory

Unlike finite measures such as a person's height or weight, the concept of vision-related quality of life cannot be directly measured. In item response theory it is assumed that items on questionnaires measure an 'underlying' or 'latent' construct[51]. In this thesis the underlying construct is called 'vision-related quality of life', which is presented on an ability-disability continuum. Since these concepts are difficult to

measure, it is important to discuss the validity and reliability of the questionnaires that purport to measure the underlying construct.

De Boer et al. have validated the questionnaires used in the present thesis, i.e. the LVQOL and the VCM1[36,39]. These latter studies were based on classical test theory, in which sum-scores are used to express the outcome measure. Modeling sum-scores is appropriate if the scores are highly reliable (e.g. if based on a large number of correlated items) and well validated. Furthermore, there should be enough variation, the distribution should be more or less normal, and no data should be missing[52]. In the example given below (see box), the sum-score for the patient would be 9 on this fictitious dimension of the LVQOL. In classical test theory, each item contributes equally to the final score of the construct that is measured, irrespective of how much an item correlates with the underlying construct[53]. However, de Boer et al. (and others) recommend to re-evaluate vision-related quality of life questionnaires with item response theory (or related models) and to describe outcomes using these models[24,28].

Example of a patient expressing his or her disability on three items of the LVQOL

How many problems do you have with:	none		moderate		great	can not perform
1. Reading labels (e.g. on a medicine bottle)	0	1	2	3	4	**5**
2. Reading large print	0	**1**	2	3	4	5
3. Writing	0	1	2	**3**	4	5

Other interesting examples of how to use item response theory models for health outcomes are also available[54-56]. There are some important advantages of using item response models. First, it supports construct validity in the sense that the meaningfulness of the measurement can be directly assessed. Fit to an item response model is empirical evidence that the observed responses can be explained by an underlying structure. Second, item response models support the handling of missing data and the use of incomplete item administration designs. Third, the models account for measurement error. Unreliability suppresses the correlation between measurements. Particularly when using questionnaires with only a few items, the correlations amongst sum-scores may be attenuated. Finally, a fourth advantage is the handling of floor and ceiling effects. Quality of life data often show a skewed distribution. In an item response model one is essentially free to specify the distribution of the underlying construct. Inferences are unbiased if the assumptions of the item response model are correct[52].

The basis of item response theory is the item (category) response curve. This curve models the relationship between a person's response to an item and their level on the underlying construct that is measured by the questionnaire. For items with

dichotomous response categories the two-parameter logistic model is often applied; this model yields an item response curve that is described by the location or item difficulty (β) and slope or discrimination (α) parameters[55].

Other models include the one-parameter logistic model (Rasch model), which assumes that all items have equal discriminating ability but differ in item difficulty. The two-parameter model allows the discrimination parameter to be different between items[53]. Models for items with polytomous response categories differ slightly in their parameterization, but all models essentially include the specification of item difficulties and a discrimination parameter[55]. For questionnaires with polytomous response categories, a model that is often used is a generalization of the two-parameter model, i.e. the graded response model[53]; this model is used in chapters 2 and 3 to evaluate the VCM1 and LVQOL. The graded response model has different discrimination and item difficulty parameters for every item[57-59]. To estimate the item difficulty parameters, the item response scale is conceptualized as a series of 5 (the number of response categories on the LVQOL for a given item minus 1) response dichotomies: (a) category 0 versus categories 1, 2, 3, 4 and 5 (β_1); (b) categories 0 and 1 versus 2, 3, 4 and 5 (β_2), etc.[57,60]. The graded response model implies using logits of cumulative probabilities[61,62], because of the cumulated probabilities of the response dichotomies that are compared. Hence, the item difficulty parameters in the graded response model represent the point along the item response curve at which the probability of a positive response in one (or more) of the response categories is 50%. Some models, such as the generalized partial credit model, compare adjacent categories to estimate parameters, e.g. category 0 versus 1; category 1 versus 2, etc.

In Figure 1, the fictitious item difficulty parameters of item 1 are β_1=-1.5; β_2=-0.5; β_3=0; β_4=1; β_5=2, and in Figure 2 of item 2: β_1=-1; β_2=-0.6; β_3=0; β_4=1; β_5=1.5. The larger the item difficulty parameter, the more of the underlying construct (also called person parameter or disability, represented by theta: ϑ) a respondent must have to endorse that response category. In Figure 1, it can be seen that a Patient A with a disability (ϑ) of 0.5 has about a 28% probability of endorsing item 1 in response category 4 (great problems) or higher. Patient B with a disability (ϑ) of 3.5 has about a 95% probability of endorsing item 1 in response category 5 (can not perform), compared to the lower response categories.

In general, the item parameters in the graded response model dictate the shape and location of the item cumulative probability curves (Figure 1 and 2) and the category response curves (Figure 3 and 4, numbered 0 to 5). The discrimination parameter represents the slope of the item response curve at the value of the item difficulty parameter, and indicates the extent to which the item is related to the underlying construct (similar to a "factor loading"). A steeper slope (i.e. a higher discrimination parameter) indicates a closer relationship to the underlying construct and is therefore

Figure 1. Item cumulative probability curves for item 1 'Reading labels'

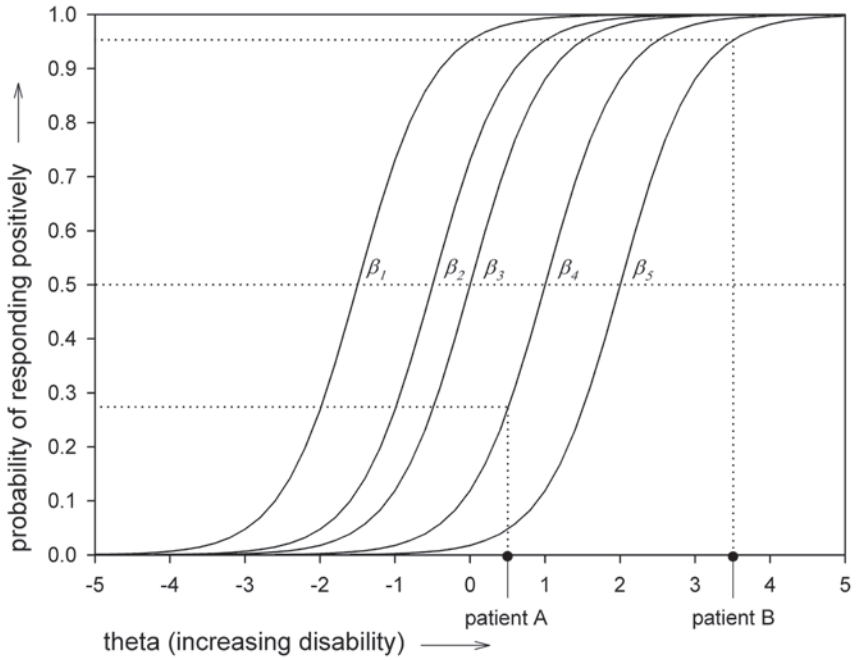


Figure 2. Item cumulative probability curves for item 2 'Reading large print'

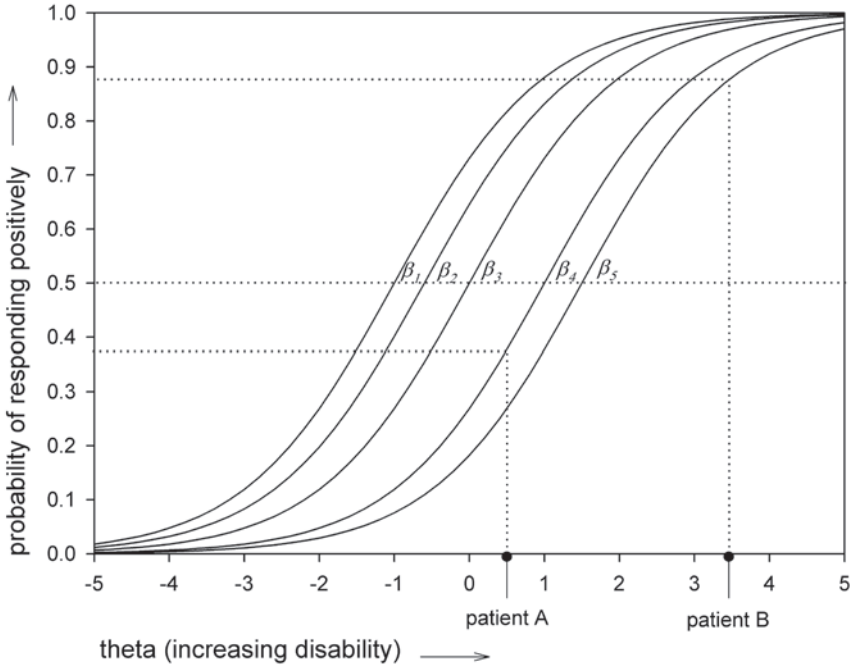


Figure 3. Category response curves for item 1 'Reading labels'

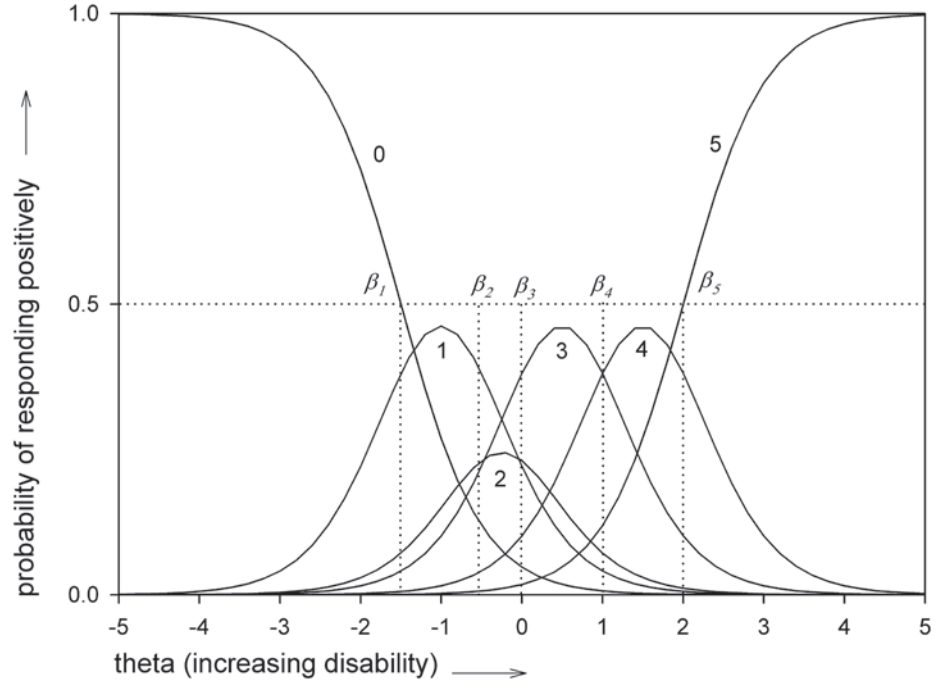
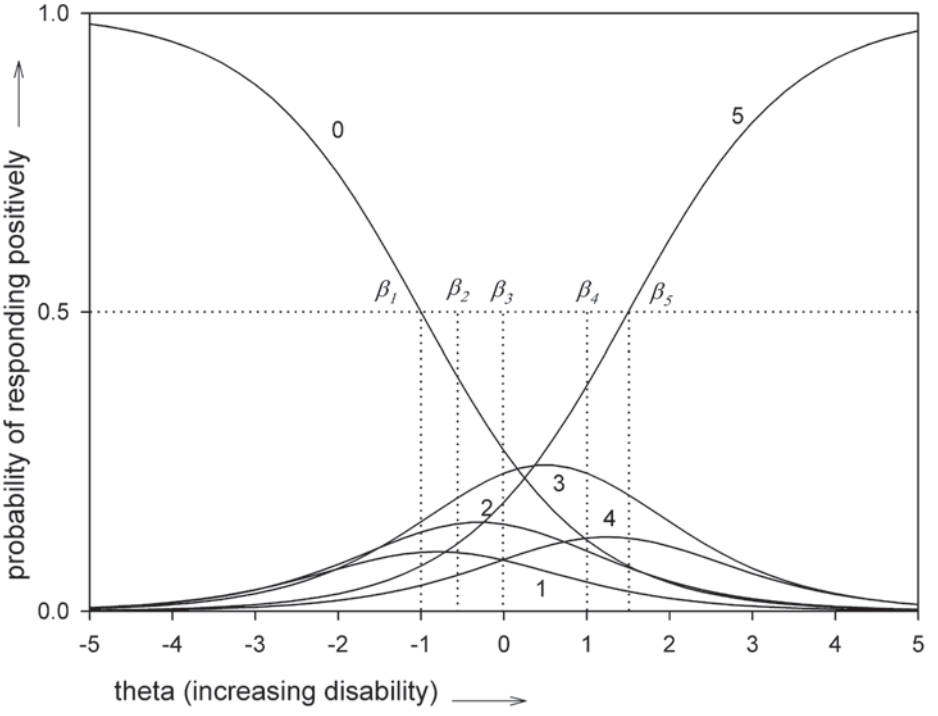


Figure 4. Category response curves for item 2 'Reading large print'



a more discriminating item[51,53,55]. In Figure 2 it can be seen that the slope of item 2 'Reading large print' is less steep (α=1) than the slope of item 1 'Reading labels' (α=2; Figure 1): The proportion of people responding in the positive direction changes relatively rapidly on item 1 as disability (ϑ) increases, compared to item 2. Therefore, item 1 is a more discriminating item. Moreover, the higher the slope parameter (Figure 1), the steeper the category response curves (Figure 3), compared with Figures 2 and 4. The item difficulty parameters (β_{ij}) determine the location of the item cumulative probability curves (Figure 1 and 2) and where each of the category response curves for the middle response options peaks (Figure 3 and 4), i.e. they peak in the middle of two neighboring item difficulty parameters (β)[51]. Category response curves are low (e.g. Figure 3, category 2) when neighboring item difficulty parameters are close together.

In Figure 1 and 2 can be seen that Patient A has a higher probability of responding positively to response category 4 (many problems) or higher of item 2, than of item 1, indicating that more of the underlying construct is needed for patients to endorse this response category or higher. In contrast, Patient B has a higher probability of responding positively to response category 5 (can not perform) versus lower categories of item 2, than of item 1. In item response models with equal discrimination parameters, a hierarchy in item difficulty parameters is obtained. This is not possible in the unrestricted graded response model.

Furthermore, item response theory is based on some important assumptions. For example, the scale is *unidimensional*, meaning that the items tap on only one underlying construct; and the items display *local independence*, meaning that the probability of answering any item in the positive direction is unrelated to the probability of any other item being answered positively on that underlying construct for persons with the same amount of the underlying construct. Only then is it possible to predict the performance of a person accurately, i.e. the person's parameter or disability (ϑ)[51,55]. Items may present local dependence when they have similar content. To prepare for item response theory analyses, these two assumptions should be checked. Moreover, it is assumed that the item response curves increase *monotonically*. Applications of item response theory implicitly assume that the model is correct; that is, the item response model should reflect the data accurately. Although a certain amount of misfit is inherent to every model, considerable misfit should be avoided. Item fit can be examined by comparing model predictions (expectations) and observed data[55]. By using item tests, decisions can be made as to whether it is necessary to omit any items. In this thesis, we used two item goodness of fit statistics known as the $S–X^2$ test by Orlando et al. (2003)[63] and Björner et al. (2005)[64].

In addition to assessing item fit, *differential item functioning* should be investigated[54]. Analysis of differential item functioning allows to examine the

relationship between item responses and another variable, such as demographic variables (gender or age group), depending on the underlying construct[65]. A large proportion of differentially functioning items in a questionnaire is a severe threat to its construct validity and thus to the ability to draw conclusions based on the test scores[66]. Furthermore, assessing differential item functioning gives an indication of whether the items are appropriate for different subgroups within populations and the generalizability for using these items in other populations. Several options are available regarding how to interpret and handle a differentially functioning item. These options will be discussed in the chapters on the psychometric properties of vision-related quality of life questionnaires.

An important characteristic of item response theory models is that reliability, or measurement *precision*, is described as a continuous function conditional on values of ϑ, the measured underlying construct. Precision is often depicted by item information curves (see chapters 2 and 3). These curves indicate the range over ϑ, where an item is best at discriminating between individuals[55]. The inverse of the square root of the information function is equivalent to the standard error (SE) of ϑ[54]. In addition, the *reliability* coefficient can be calculated for ϑ, which reflects the persons fitting the data (index of subject separation)[67].

Longitudinal outcomes of low-vision rehabilitation

This section presents an overview of the low-vision rehabilitation system in the Netherlands and the criteria for referral to these services. In addition, the rationale is described for using a multilevel item response model to analyze the longitudinal low-vision rehabilitation outcomes.

Low-vision rehabilitation services in the Netherlands

In most studies described in this thesis, patients were referred to low-vision rehabilitation services by their ophthalmologist. The longitudinal outcomes of these Dutch rehabilitation centers have been observed. Obviously, rehabilitation was not always available. In the 19th century several local initiatives were established, but these were mostly aimed at blind children or children with multiple handicaps. Although no real rehabilitation was available, in the blind institutions some education was given. In 1843 the first institution for adults was founded in Amsterdam. Blind adults were taught skills in order to make money and survive (e.g. to make reed baskets or doormats). Over the years, these local initiatives increasingly started to cooperate.

Nowadays, in the Netherlands there are two main types of rehabilitation: monodisciplinary low-vision rehabilitation (provided by optometrists), and

multidisciplinary low-vision rehabilitation (provided by regional centers). The main goal of low-vision rehabilitation services is to enhance ability with the patient's remaining vision. Care provided by both services is financed by the Exceptional Medical Expenses Act (known as the *Algemene Wet Bijzondere Ziektekosten; AWBZ)*. Ophthalmologists, general practitioners or other physicians can refer patients to low-vision rehabilitation services. Patients are also allowed to contact these services on their own behalf. Nowadays, visually impaired patients and their ophthalmologists seem to be more aware of the possibilities for rehabilitation. In modern society with its rapidly changing demands, people with mild vision loss (i.e. visual acuity between 0.3 and 0.5) increasingly ask for low-vision aids or for a referral to low-vision rehabilitation. In 2004, an evidence-based guideline for referral of visually impaired persons to low-vision services was developed[68-70]. Several recommendations were made, including recommendations as to what type of patient is eligible for referral. These were a visual acuity ‹0.5; or, a reading acuity ‹0.25; or, visual field defects ‹30° of fixation; or, other severe field defects, e.g. hemianopsia; and, relevant vision-related problems in daily life which cannot be addressed by interventions in standard ophthalmic practice, and which can potentially be solved by visual rehabilitation. Recommendations were also made about which patients need low-vision aids or training for complex aids (e.g. telescope systems), and how/what to communicate to patients (e.g. the diagnosis, delivery of 'bad news', or presence of Charles Bonnet syndrome). Other recommendations concerned written information to be given to patients; communication with general practitioners and other clinicians involved in referrals; and referral of patients to other sub-specialties. In addition, a follow-up consultation and/or a second opinion were recommended in specific situations.

Optometrists, who provide monodisciplinary services, usually work for commercial firms which are based either in hospitals or in the community. The optometrists in hospitals mainly treat patients who are referred by ophthalmologists. An optometrist assesses a patient's visual functioning and the problems a patient experiences in daily life. Taking this into account, the patients are informed which low-vision aids might be suitable and receive instruction on their use. Optometrists mainly prescribe optical aids, such as various types of magnifiers, telescope systems and closed-circuit television systems (CCTV). A CCTV provides the largest possible magnification. Optometrists refer their patients to multidisciplinary services in case of complex needs, in addition to visual impairment problems. Optometrists in the Netherlands are not permitted to prescribe drugs or perform invasive interventions.

Multidisciplinary services have regional outpatient centers in various Dutch cities; these services offer several options for the patient. All patients receive a general intake consultation to assess their rehabilitation needs. Patients are then screened by a low-vision specialist or optometrist for visual acuity, visual field, contrast

sensitivity, lighting problems, etc. If more rehabilitation needs are revealed then more possibilities are available (e.g. occupational therapy, visit to a psychologist or social worker). In addition to the above-mentioned services, training in Activities of Daily Living (ADL) and mobility, and advice on adaptations in the home environment, are offered by occupational therapists. Also, some multidisciplinary centers offer individual or group counseling, art and music groups, computer training, etc.

Until recently, there were three organizations with outpatient regional centers: Visio, Sensis and Bartiméus. However, to better cope with current demands and be more effective, the organizational structures were adapted. In 2008, the boards of Visio, Sensis and De Brink merged to become the Visio-Sensis-De Brink Group. The organizations also offer inpatient facilities, e.g. for adults with multiple handicaps, or schools for children. De Brink is an example of an inpatient institution for (young) adults and children with multiple handicaps, including visual or other sensory impairments and mental disabilities. Inpatient facilities providing, for example, job training, ADL/mobility training or recreational activities are found in Visio-Het Loo Erf (merged in 2002) and Bartiméus (with a facility previously known as Sonneheerdt; merged in 2006). One of the studies in this thesis was conducted among adult patients from Visio-Het Loo Erf. In addition, a few nursing homes for visually impaired elderly work together with, or are part of, these organizations.

In addition to rehabilitation, other types of low-vision support include network organizations such as Viziris, which has member organizations concerned with visually impaired persons: i.e. organizations for patients with macular disease, glaucoma, retinal disease, visual impairments in general, for parents with visually impaired children, or for persons with guide dogs. Other organizations that are not a member of Viziris, such as the Diabetes organization, aim to help patients with diabetic retinopathy. These patient organizations, using either professionals or (visually impaired) volunteers, provide patients with practical information and support. Many ophthalmology departments have information/brochures about how to contact these patient organizations. Finally, several funds are available that provide financial assistance to visually impaired individuals with specific needs that are not covered by regular health insurance.

Applying longitudinal item response theory modeling

One of the main goals of this thesis is to investigate the longitudinal outcomes of mono- and multidisciplinary low-vision rehabilitation services. To assess the effects of low-vision rehabilitation, classical measures are often used, such as a T-test (or repeated measures ANOVA). With a T-test, the statistical longitudinal problem is reduced to a cross-sectional problem. T-tests are not suitable for analysis of the relationship between the development of two continuous variables, or to simultaneously compare

developments between different groups, or between a continuous outcome variable and several predictor variables[71]. Similarly, with repeated measures ANOVA, having missing observations on questionnaires or single items is problematic. In general, changes over time can be analyzed with more advanced techniques of longitudinal data analyses[71,72], such as multilevel analyses, where modeling occurs at different levels simultaneously (within and between persons). These mixed models allow assessment of individual change over time. Models with a mixture of fixed effects (that do not vary between persons, i.e. group effects) and random effects (that do vary between persons) are called mixed models[73]. In addition, in this thesis a step was made beyond this advanced longitudinal analysis, because the aim was to describe two sides of the data matrix, i.e. to measure outcomes and to simultaneously investigate an explain the data: The measurement approach seeks to describe the performance of individual patients, whereas the explanatory approach seeks to relate the item responses on a questionnaire to other variables belonging to patients (person predictors) or pertaining to items (item predictors)[73]. Consequently, and also based on previous investigations by Pastor et al.[74], the multilevel item response model was chosen, which is a special case of a generalized linear mixed model. The term 'generalized' refers to the freedom of a transformation of the mean of the expected value, i.e. the link function ('logit' in this thesis)[73]. An advantage is that standard software can be used to implement these models, such as SAS, Stata, M-plus, R, etc.

The basics of item response theory are described in the previous section. The general idea for the multilevel item response model is that it assumes that the positions of persons on the underlying construct measured (i.e. vision-related quality of life; measured on an ability-disability continuum), change over time. However, item responses at different time points are also dependent[61]. The multilevel item response model allows the assessment of individual effects (in addition to the average group effects) at different time points. Moreover, the model allows to explore the item invariance assumption across occasions by assessing item by time interactions at different time points, which is an indication of the validity of the questionnaire. This enables to see whether the measured construct remains stable over time, and also to confirm that the items are not interpreted differently over time (response shift). A generalized linear mixed model is more likely to be a valid longitudinal model in case of missing data[75,76]; this made it a highly feasible approach for the data described in this thesis. Particularly in the longitudinal study, at the final measurement point (4.4 years after baseline) many observations and data were missing. One of the important advantages of item response models already mentioned before is that these models handle missing data adequately and incomplete item administration designs can be used. Items that are calibrated on a common scale can be chosen for specific patient groups, which greatly improves the efficiency of data collection. One

can also effectively deal with problems specific to longitudinal research where items differ across waves, for example in case of missing data across time-points. In recent simulation study by Glas et al. it was shown that even when a considerable amount of data was missing, the power to detect effects was comparable to the power obtained when the responses of all patients to items were complete[77]. In the multilevel item response model, the item difficulty parameters (β), the person parameter (ϑ), the time and treatment effects, and several confounders to adequately deal with missing values (chapter 7), were all included in the same model.

Co-morbidity and health-related quality of life of older visually impaired patients

Apart from common eye conditions that cause low vision and blindness in older patients[3], many also suffer from other (chronic) conditions. The term co-morbidity is defined as "*any distinct additional clinical entity that has existed or that may occur during the clinical course of a patient who has the index disease under study*"[78]. The co-occurrence of chronic conditions, i.e. multi-morbidity, is a common phenomenon in older adults and is considered a major threat to the quality of life[79,80]. An association is reported between the number of conditions and quality of life, whereby a higher number of diseases is related to deterioration of physical functioning[81-84], or social and psychological functioning[85]. The prevalence rates of several conditions, including having several chronic conditions at once, increase with age[86]. A recent Dutch study found that the prevalence of multi-morbidity increased from 39% to 53% for persons aged 55 to 64 years, and from 83% to 95% for persons older than 85 years[87]. It is also reported that multi-morbidity increases healthcare utility, medical care costs, and mortality[81,85,88].

Langelaan et al. (2007) showed that different chronic conditions have a different impact on health-related quality of life. They concluded that having a visual impairment had a detrimental effect on health-related quality of life compared to e.g. diabetes mellitus, coronary syndrome and hearing impairments. In contrast, having a visual impairment had less impact on quality of life than some severe neurological (e.g. stroke, multiple sclerosis) and mental conditions (e.g. major depression)[89]. In other studies among visually impaired older patients, co-morbidity was often reported. For example, Brody et al. found that 78% of older patients reported to have at least one other condition in addition to age-related macular degeneration. In studies on co-morbidity in cataract patients and patients with diabetic retinopathy, in addition to diabetes, heart conditions and mostly hypertension were often diagnosed[90,91]. It is known, however, that older patients often have problems in recalling co-existing conditions when asked in a clinical setting. In this thesis, self-reports on co-morbidity

from visually impaired patient were compared with reports from their general practitioners. In the Netherlands, general practitioners usually have an individual's medical history, receive results of all clinical investigations and treatments and, therefore, should have an up-to-date and complete record of the patient's medical status.

Some multi-morbidity studies have investigated older adults with dual sensory impairments[92-94]. These studies concluded that the combination of a visual and a hearing impairment had a detrimental impact on health outcomes such as physical activity, social participation, depression and psychosocial functioning. In the Netherlands, the number of older adults with such an acquired dual sensory impairment was estimated to be 30,000 to 35,000 persons, and most common in persons aged 85 years or older[95]. Other (chronic) condition combinations (in addition to a visual impairment) may also have a detrimental impact on quality of life[80,81]. Insight into combinations which lead to a worse quality of life is important for individual care, as well as for public health purposes[80].

In this thesis we investigated which co-existing conditions and patient characteristics lead to an increased vulnerability, or a decline in terms of health-related quality of life, among visually impaired older patients.

Objectives and outline of the thesis

In the following chapters, most analyses were performed on an existing dataset constructed by M.R. de Boer and G.H.M.B. van Rens, who started the longitudinal study on rehabilitation outcomes in 1999. Baseline measurements took place between July 2000 and January 2003; follow-up measurements were performed after approximately 5 months and after 1 year. For this thesis, a final measurement cycle was performed between July 2005 and January 2007 with the aim to investigate the long-term outcomes of rehabilitation after about 4 to 5 years.

The objectives of the work in this thesis are:

1. To assess the psychometric quality of vision-related quality of life questionnaires;
2. To measure the longitudinal outcomes of low-vision rehabilitation in a visually impaired older patient population;
3. To investigate co-morbidity of older visually impaired patients and its relation to health-related quality of life.

Psychometric quality of vision-related quality of life questionnaires

The recommendation to reevaluate vision-related quality of life questionnaires within item response theory models was the basis of many chapters in this thesis.

Chapter 2 describes the psychometric quality of the Vision-related quality of life Core Measure (VCM1) in the visually impaired older patient group. To assess the use of the questionnaire for screening, item interpretation is compared to participants from a community-based sample with low vision from the Longitudinal Aging Study Amsterdam (LASA)[96]. LASA is an ongoing cohort study on predictors and consequences of changes in autonomy and well-being in the aging population in the Netherlands. Data collection in LASA started in 1992-1993 and was followed by data collection cycles every 3 years. For this thesis, data of the fourth measurement cycle in 2001-2002 were used, in which visual acuity and the vision-related quality of life of part of the LASA sample were measured for the first time in face-to-face interviews. **Chapter 3** presents the psychometric quality and differential item functioning of the Low Vision Quality of Life questionnaire (LVQOL). In **chapter 4**, a reevaluation of the National Eye Institute-Visual Functioning Questionnaire–25 (NEI-VFQ-25) is conducted with a partial credit model on data from a younger working-age adult population who were rehabilitants at Visio-Het Loo Erf (an inpatient low-vision rehabilitation service). Finally, **chapter 5** provides a brief comment on a review article on vision-related quality of life questionnaires for patients with age-related macular degeneration.

Longitudinal outcomes of low-vision rehabilitation

In the following chapters, a special case of a generalized linear mixed model (i.e. the multilevel item response theory model) was investigated to describe the longitudinal outcomes of low-vision rehabilitation in the older visually impaired patient population. Results are given for the 5-month and 1-year outcomes (**chapter 6**) and for the 4.4-year outcomes (**chapter 7**). In addition, **chapter 8** presents a summary of a systematic review on evidence-based outcomes of low-vision rehabilitation.

Co-morbidity of older visually impaired patients

Chapter 9 investigates levels of agreement regarding co-morbidity, as reported by visually impaired older patients compared with their general practitioner. Subsequently, **chapter 10**, explores a risk profile of patient characteristics and co-existing diseases related to quality of life and its decline in our population.

General discussion and summary

Chapter 11 presents a summary of the chapters, a discussion, and a general conclusion. In addition, some limitations of our studies are addressed, and recommendations are made for future research and clinical practice. Finally, **chapter 12** concludes this thesis with a summary in Dutch.

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PART IV

Concluding chapters

CHAPTER 11

Summary & general discussion

Background

Large Western population-based studies have reported that prevalence rates for visual impairment and blindness range from 0.6 to 2.1% and from 0.1 to 0.9%, respectively[1] and that the prevalence of visual impairment increases rapidly after the age of 65, and blindness after the age of 85 years[1,2]. It is estimated that between 2005 and 2020 the number of Dutch visually impaired adults will increase by 18.7% from approximately 298,000 persons in 2005 to 354,000 persons in 2020[3]. This increase is mainly due to aging of the population. In Western countries, the most common causes of visual impairment (which includes low vision and blindness) are age-related macular degeneration, cataract, diabetic retinopathy and glaucoma. For visually impaired persons, low-vision rehabilitation is an important treatment option[4].

Especially when cure is not expected (as in visually impaired patients with irreversible eye conditions) it is nowadays widely accepted that any treatment choice should also take into account the patient's quality of life, which covers physical, psychological and social functioning. In addition to quality of life in general, the patient's subjective perception in terms of vision-related quality of life is increasingly recognized as a meaningful representation of the patient's visual disability before and after medical treatment or rehabilitation[5,6]. Over the years, many vision-related quality of life questionnaires have been developed[5,7,8]. In this thesis, three vision-related quality of life questionnaires are evaluated within item response models, namely the Vision-related quality of life Core Measure (VCM1), the Low Vision Quality Of Life questionnaire (LVQOL) and the National Eye Institute - Visual Function Questionnaire (NEI-VFQ-25). In item response theory it is assumed that items on questionnaires measure an 'underlying' construct[9]. The concept of vision-related quality of life is perceived as an underlying construct since it cannot be directly measured, in contrast to measures such as a person's height or weight. In addition, a brief comment is given concerning a review article on vision-related quality of life questionnaires for patients with age-related macular degeneration.

Next, we describe the longitudinal outcomes of low-vision rehabilitation of older patients (N=296; mean age 78 years at baseline) who were referred to monodisciplinary or multidisciplinary low-vision rehabilitation services in the Netherlands. In addition to the relatively short-term effects (5-month and 1-year follow-up), it was considered important to gain insight into the long-term effects (4 to 5 years follow-up). This enabled us to understand how patients experience their quality of life when most of them had stopped attending low-vision rehabilitation services some time ago. Baseline measurements took place between July 2000 and January 2003. To investigate the long-term outcomes of rehabilitation, an additional measurement cycle was performed between July 2005 and January 2007. A multilevel

item response model was investigated to describe the longitudinal outcomes of low-vision rehabilitation. In addition, a summary of a review regarding evidence-based low-vision rehabilitation outcomes in terms of quality of life is described.

Finally, apart from common eye conditions that cause low vision and blindness, many older patients also suffer from other (chronic) conditions. Moreover, co-morbidity is considered to be a major threat to quality of life[10,11]. Insight into those combinations that lead patients to experience a worse quality of life is important for the individual care of patients, as well as for public health purposes[11]. It is known, however, that older patients may have problems recalling co-existing conditions when asked about this in a clinical or research setting. In the Netherlands, the general practitioner (GP) usually has an up-to-date and complete record of the patient's medical status. Therefore, co-morbidity reports from visually impaired patients were compared with reports from their GP. In addition, we explored which co-existing conditions and patient characteristics led to an increased vulnerability or to a decline in terms of health-related quality of life in these patients.

The objectives of this thesis were threefold:

1. To assess the psychometric quality of vision-related quality of life questionnaires;
2. To measure the longitudinal outcomes of low-vision rehabilitation in a visually impaired older patient population;
3. To investigate co-morbidity of older visually impaired patients and its relation to health-related quality of life.

The following sections present a summary of the results for these topics, and discusses some methodological considerations and implications and recommendations for research and practice. This chapter ends with some general conclusions.

Psychometric quality of vision-related quality of life questionnaires

This section presents a summary and discussion of the concept of vision-related quality of life, the questionnaires used, and the psychometric quality of these questionnaires as assessed with item response models.

Summary of the results

In the past decades many vision-related quality of life or visual functioning questionnaires have been developed[5,7,8]. In this thesis, the psychometric quality of the Dutch versions of the VCM1, the LVQOL and the NEI-VFQ-25 was further investigated using methods from item response theory. Table 1 shows the methods used to assess the psychometric quality of the questionnaires, including the software used.

Table 1. Methods and software used to assess the psychometric quality of the questionnaires

Psychometric properties	VCM1 and LVQOL	NEI-VFQ-25
Exploratory factor analyses (rotation)	Polychoric correlations (promax)	Polychoric correlations (promax)
- Software	- Mplus	- Mplus
Item response model	Graded response model	Partial credit model
- Software	- gllamm (Stata)	- RUMM2020
	- MULTILOG	
Item-test	S–X^2-test	Item-trait interaction (χ^2)
- Software	- SAS	- RUMM2020
DIF analyses	Likelihood Ratio (G^2)	ANOVA
- Software	- IRTLRDIF	- RUMM2020
Precision	Item & test information	Person-item distribution
- Software	- MULTILOG	- RUMM2020
Reliability	Index of person separation	Index of person separation
- Software	- MULTILOG	- RUMM2020

Table 2 lists the psychometric properties of the three Dutch questionnaires, i.e. dimensionality, local (in)dependence, monotonicity, differential item functioning (DIF), precision and reliability, as well as the items that were deleted (see Chapter 1 for an explanation of these terms). The psychometric quality is described separately for the questionnaires, including additional information from other studies.

Table 2. State-of-the-art of the Dutch VCM1, LVQOL and NEI-VFQ-25 assessed with item response models

Psychometric properties	VCM1	LVQOL	NEI-VFQ-25
Dimensionality	1 dimension	4 dimensions	4 dimensions
-Dimensions (final number of items)	VRQOL (10)	Basic aspects (5)	Near activities (5)
		Mobility (4)	Distance activities & mobility (8)
		Adjustment (4)	Mental health & dependency (6)
		Reading & fine work (7)	Pain & discomfort (3)
-Eigenvalues†	6.3	12.9; 2.1; 1.2; 1.0	5.3; 3.3; 1.9; 1.4
-Explained variance†	63%	75%	54%
Local dependence (suspected)	Item 9	None	Item 4, 19
Monotonicity: item misfit	None	None	Item 19, 21
Differential item functioning (DIF)§:			
-Gender	None	Item 1, 12, 24	Item 14
-Age group	None	None	Item 10, 12, 19
-Independent living	n.a.	n.a.	Item 14
-Co-morbidity	n.a.	n.a.	None
-Educational level	n.a.	n.a.	None
-Eye condition	None	Item 19	n.a.
-Visual acuity	None	Item 3, 7	n.a.
-Functional vision score	n.a.	n.a.	None
-Time onset visual impairment	n.a.	n.a.	Item 8, 11, 19
-Rehabilitation type	None	None	n.a.
-Administration type	Item 9, 10	Item 1	n.a.
-Population type	Item 6, 9, 10	n.a.	n.a.
-Time (item invariance not assumed)	Item 2, 4, 6, 9, 10	Item 10, 14, 18, 19, 20	n.a.
Precision			
-Item information (highest/lowest)	Item 4/item 1	n.a.	n.a.
-Test information (highest)	VRQOL	Reading & fine work	n.a.
Reliability			
-Cronbach alpha(s)*	0.92	0.93; 0.84; 0.82; 0.90	n.a.
-Index of person separation*	0.93	0.91; 0.94; 0.86; 0.83	0.83; 0.75; 0.66; 0.66
Omitted items	None	Item 1, 5, 24, 25	Item 15, 16, 16a

VRQOL: vision-related quality of life; n.a. not assessed; † Eigenvalues and explained variance for the LVQOL without item 5 and 25; for the NEI-VFQ-25 without item 15, 16 and 16a; § underlined DIF items: non-uniform DIF; other DIF items: uniform DIF; * respectively for the dimensions.

Vision-related quality of life Core Measure (VCM1)

The purpose of the study described in **chapter 2** was to investigate the psychometric quality of the VCM1 in a visually impaired patient population using an item response theory approach. In addition, it was established whether the VCM1 was able to screen for problems related to vision loss in the community.

Dimensionality was investigated on the baseline measurements of the longitudinal study among visually impaired older patients (mean age 78 years; see also chapter 6). The VCM1 consisted of one dimension, which is in accordance with an earlier study[12]. Local independence of the items was also investigated. Item 9 'Inability to do preferred activities' was suspected but, although it was previously recommended to omit this item[13], the residual co-variation with other items was initially not considered a problem.

Monotonicity was investigated; all items showed fit to the graded response model, including item 9. In contrast, when analysis with a Rasch rating scale model was performed on the VCM1 completed by patients from a low-vision clinic and a cataract surgery waiting-list, a lack of item fit to the Rasch model was found when both populations were taken together[12]. This difference in results might be due to the different models used. Rasch models are considered to be stricter and more parsimonious, because in the unrestricted graded response model (which we used) the discrimination parameter is allowed to vary between items. However, less constrained models often give a more accurate reflection of the data[9]. An indication of construct validity was obtained with analyses of differential item functioning (DIF). No interference was found between item responses of patients on the relevant group variables listed in Table 2. This indicates that the VCM1 can be applied to relatively heterogeneous groups of visually impaired patients. However, DIF was found on item 9 'Inability to do preferred activities' and 10 'Life interference' between administration type subgroups, i.e. patient self-reports versus patients who were assisted by proxy (often a relative or spouse); however, because the maximum difference in expected scores was not large, no items were omitted. After the psychometric quality in the patient sample had been evaluated, we explored whether the item estimates of the VCM1 could be generalized to persons with vision loss from the community-based sample of the Longitudinal Aging Study Amsterdam (LASA). DIF was present on item 6 'Safety at home', and again on items 9 and 10; on item 6 the expected score was almost one point lower for the community-based sample at higher disability levels. Therefore, it was concluded that the VCM1 is not instantly appropriate for screening in the community because the DIF items might threaten the construct validity of the VCM1. Furthermore, in chapter 6 it emerged that a possible limitation is that the VCM1 seems less appropriate for measuring the effects of low-vision rehabilitation. It was found that, across different follow-up time points, some items had DIF. This implies

that change could not be accurately measured in visually-disabled patients using this questionnaire[14]. De Boer et al. also found responsiveness and reproducibility to be only moderate. Furthermore, in the study of Lamoureux et al. DIF was present on a number of items between the low-vision and cataract samples, which could not be resolved[12]. They did not report, however, which items had DIF or how large differences between scores should be in order to be considered a problem. However, they decided to fit the model for both populations separately.

The precision of the items and the test (VCM1) was investigated with item and test information curves. We found that the VCM1 covered the whole disability continuum of the visually-impaired older patient population. Some items, (e.g. item 4 'Depression') were more informative and precise across the disability continuum. Item 1 'Embarrassment' was the least precise (especially at the lower levels of disability), but the overall precision of VCM1 items was acceptable. Finally, the reliability of the questionnaire was satisfactory, with an index of person separation of 0.93 reflecting acceptable person fit to the model. Satisfactory internal consistency of the VCM1 was also reported in another study, with a similar explained variance of ›60%[15].

The psychometric quality of the VCM1 seemed satisfactory based on item fit to the graded response model and most differential item functioning outcomes. However, DIF analyses showed that the VCM1 was problematic between subgroups with different types of administration. Anchoring and deleting items, or collapsing response categories, did not substantially improve the psychometric quality of the VCM1. Therefore, the VCM1 was kept intact. In future, when using the VCM1 as a disability measure or screening tool, item parameters of differentially functioning items might need to be modeled. Moreover, responses on the VCM1 of persons in the LASA sample with a visual acuity of the best-eye of ‹0.5 were investigated. This visual acuity measure may not have been the best criterion for assessing screening properties. Bearing in mind uncertain construct validity reported in earlier studies and in this thesis, future use of the VCM1 should be considered with caution.

Low Vision Quality Of Life questionnaire (LVQOL)

The purpose of the study described in **chapter 3** was to re-evaluate the psychometric quality of the LVQOL using an item response theory model.

Dimensionality was investigated on the baseline measurements of the same group of visually impaired older patients (see also chapter 6). After omission of item 5 'Problems reading street name signs' and item 25 'Problems in performing household tasks' because of low factor loadings and confusing interpretation of factors, the final solution of the LVQOL consisted of four dimensions: "Basic aspects", "Mobility", "Adjustment" and "Reading and fine work". However, compared to the final factor solution according to the original LVQOL by Wolffsohn et al.[16], the Chinese version

by Zou et al.[17] and the confirmatory factor analysis by de Boer et al.[13], there was a (slightly) different item-spread. This may have been caused by cultural differences[17] or the choice of psychometric techniques. Furthermore, local independence could be assumed for all items. Monotonicity was investigated; all items showed fit to the graded response model.

An indication of construct validity was obtained with DIF analyses. DIF was found on five items between subgroups of gender, visual acuity, administration modes and eye conditions (Table 2). Two items were omitted: one because the maximum difference between expected scores exceeded one point (item 24 'Using tools' from the "Reading and fine work" dimension), and another because DIF was found on multiple relevant background variables (item 1 'Vision in general' from "Adjustment"). With regard to DIF over time, this was assessed again for the two dimensions after removal of both items. Initially, the factor loadings of the three "Reading small print" items of the "Reading and fine work" dimension were very high (›0.92), compared to the other items (between 0.53 and 0.79), which may have indicated another construct. However, a five factor solution was not found. In addition, the "Reading small print" items were probably very sensitive to the statement in the questionnaire about administering the questionnaire '*... as if you were using your glasses or low-vision aids'*. Or, as was suggested by Stelmack et al.[18], the items may have been more sensitive to change because of the reading aids which were received by many patients. The mixture of items on the "Reading and fine work" dimension (consisting of the "Reading small print" subdimension and the "Visual (motor) skills" subdimension), may have confounded the outcome of low-vision rehabilitation if the rehabilitation program mostly consisted of enhancement of reading skills instead of visual (motor) skills. Items on the subdimension "Reading small print" improved more than items on the "Visual (motor) skills" subdimension. Therefore, no improvement was found on the entire "Reading and fine work" dimension after low-vision rehabilitation. Probably because almost everyone received reading aids, the three "Reading small print" items were interpreted as being easier after low-vision rehabilitation.

Furthermore, after omitting item 24 'Using tools', the assumption of item parameter invariance across time points could still not be maintained for the "Reading and fine work" dimension. Consequently, for longitudinal assessment of outcomes, dividing the dimension in two subdimensions "Reading small print" and "Visual (motor) skills" is probably still indicated. However, item fit is inappropriate for the "Reading small print" subdimension. In contrast, after omitting item 1 'Vision in general', item invariance was assured on the short and long-term time points for the "Adjustment" dimension, indicating that the outcome on this dimension can be appropriately assessed.

In chapter 3, the precision of the dimensions of the LVQOL was further explored with test information curves. Test information showed full coverage of the disability continuum. The "Reading and fine work" and "Mobility" dimensions were most informative for differentiating among patients' disability levels in terms of vision-related quality of life. This result is in accordance with studies reporting that visual ability is a composite variable with at least two sources of variability: the first dimension had most impact on responses to items related to reading and visual motor tasks, and the second dimension was described by mobility items[19,20]. For the LVQOL, the "Mobility" dimension was the first factor and "Reading and fine work" the second factor. The third factor was "Adjustment", which is in line with a study on the factor structure of the Impact of Vision Impairment questionnaire (IVI), where an "Emotional well-being" dimension was found in addition to a mobility and a reading dimension[21].

Finally, the reliability of the questionnaire was satisfactory, with indices of person separation between 0.83 and 0.94, representing good person-fit. The internal consistency was also shown to be satisfactory, with adequate Cronbach alphas. The dimensions of the LVQOL accounted for 75% of the total variance.

The adapted LVQOL with 21 items seems highly appropriate for use in heterogeneous populations of visually impaired patients. However, the "Reading and fine work" dimension needs further assessment in relation to DIF over time (item invariance) in outcome studies.

National Eye Institute - Visual Function Questionnaire–25 (NEI-VFQ-25)

The purpose of the study described in **chapter 4** was to obtain the factor structure of the Dutch version of the NEI-VFQ-25 and interval scales using a partial credit model.

Dimensionality was investigated on the baseline measurements of a population of 129 visually impaired adults (mean age 42 years) who were participating in an inpatient low-vision rehabilitation facility. It was previously suggested that the NEI-VFQ probably did not consist of more than four factors[22]. Similarly, after omitting the 'Driving' items 15, 16 and 16a because of ceiling effects and missing values, this suggestion was confirmed because the factor analysis in this study indicated four factors: "Near activities", "Distance activities & mobility", "Mental health & dependency", and "Pain & discomfort". In some studies the driving items were kept in the original NEI-VFQ-25 because driving was perceived as being highly valued, and persons may seek eye care due to problems with driving[23]. In a severely visually impaired population, i.e. the adult working-age population described in chapter 4, these items were less relevant. In the Netherlands (and other countries) driving with a best corrected visual acuity ‹0.5 is prohibited by law. The driving items were also

omitted in the Chinese and Japanese NEI-VFQ-25 studies[24,25] and were found to be problematic in the French version of the NEI–VFQ-25[26].

Local independence was not investigated as such; however, item 19 ("How much pain or discomfort in or around your eyes keeps you from doing what you'd like to be doing?") had a high correlation with item 4 ("How much pain or discomfort have you had in and around your eyes?"; r=0.65), which may indicate local dependence for these items.

Monotonicity was explored with separate analyses on each factor, where goodness-of-fit with the χ^2 item-trait interaction statistics and step thresholds were examined. Most items showed some degree of disordering. After collapsing response categories, all items showed ordered thresholds. The "Near activities" dimension showed excellent fit, the "Distance activities & mobility" and the "Mental health & dependency" good fit, and the "Pain & discomfort" dimensions had a significant item-trait interaction that indicated misfit to the model. Item 21 'Feel frustrated' of "Mental health & dependency" and item 19 'Pain in or around the eyes' of "Pain & discomfort" were identified as misfitting items. Addition of other items, or using the longer version of the NEI-VFQ, may improve the fit to the model.

An indication of construct validity was obtained with DIF analyses. Items 8 'Reading street signs', 10 'Noticing objects off to the side', 11 'Seeing how people react', 12 'Picking and matching clothes', 14 'Going out' and 19 'Pain in or around the eyes' had DIF. Item 12 was an item with almost equal loadings on "Near activities" and "Distance activities & mobility". It might be an option to delete items that show DIF. For example, item 19 was a misfitting item that was suspected of local dependence and had DIF on two relevant group variables. However, this may be a too rigorous decision based on the small sample size (N=129), and items with DIF do not always produce poor measurements[27]. Also, the magnitude of DIF was not assessed, and the weak to moderate correlations between the four subscales (|r|=0.01 to 0.42) indicate that the scales measure different aspects of quality of life.

Finally, the reliability of the questionnaire was satisfactory for the "Near activities" dimension, but unsatisfactory for the "Distance activities & mobility", "Mental health & dependency" and "Pain & discomfort" dimensions because of indices of person separation ‹0.80. The dimensions of the NEI-VFQ-25 accounted for 54% of the total variance. Internal consistency was also assessed in other studies, but was based on different factor structures[23-26,28,29].

In conclusion, the results of the current study suggest that modifications of the original NEI-VFQ-25 structure are needed when using the questionnaire in a sample of working-age visually impaired adults. It would be interesting to investigate the psychometric quality of the Dutch version of the NEI-VFQ-25 in an older visually impaired population using item response models. The studies of Massof and

Fletcher[22] and Stelmack et al.[30] showed that item location order in the elderly differed from that in the working age population described in chapter 4. Furthermore, the study by Stelmack et al. reported that the four items of the NEI-VFQ-25 sensitive to change after rehabilitation were probably related to the rehabilitation or low-vision aids received by most of the patients[30]. At this stage, the Dutch questionnaire could be improved by collapsing response categories, removal of items with poor fit statistics and DIF items, and by adding meaningful items to the dimensions or using the supplemental items. Until these deficiencies are addressed, NEI-VFQ-25 scores and results from outcome studies must be interpreted with caution. Similar warnings have been published earlier[24,25,29,30].

Methodological considerations and future research

Researchers seem to have improved the field of health assessment by applying methods from item response theory to their questionnaire development and psychometric evaluation; some of these methods were developed even in the early 20th century. Interesting examples on how to use item response models for health outcomes are available[31-33], and application should become easier when more user-friendly versions of the software become available.

In this thesis, the recommendation by de Boer et al. and others to reevaluate vision-related quality of life questionnaires with item response theory or related models, and to describe outcomes with these models, was successfully followed[7,34]. This does not mean, however, that the work on the Dutch versions of the VCM1, the LVQOL and the NEI-VFQ-25 is finished. The psychometric quality of the three questionnaires is not yet perfect and some areas of psychometric evaluation still need to be addressed.

When using the VCM1 in future studies, it is recommended to use one administration type, or to model separate item parameters when patients are assisted by proxy[35]. The VCM1 can be used to screen for vision-related problems in the community. However, when planning to simultaneously take into account generalizability to other patient populations, item parameters of three VCM1 items also need to be modeled. The screening purposes of the VCM1 need to be further assessed, for example by relating VCM1 scores to stenopeic visual acuity (e.g. to explore refractive error) or questions on recognizing persons at a certain distance and reading performance, which are available in the LASA study. It would be interesting to compare vision-related quality of life in the LASA community-based population with earlier studies from the UK where the response category >2 'More than a little concern' was taken as the impairment threshold[36,37].

The adapted LVQOL with 21 items seems highly appropriate for use in heterogeneous populations of visually impaired patients. However, the "Reading and fine work" dimension needs further assessment related to DIF over time (item

invariance) in outcome studies. On this dimension, the "Reading small print" items seemed more sensitive to change than the other items. The factor structure should also be confirmed in future studies.

Given the relatively small sample in the NEI-VFQ-25 study, the generalizability of the findings should be further investigated. The newly developed factor structure should be validated, and the original factor structure should be invalidated in new studies using confirmatory factor analysis. The addition of new items relevant to the factors could further improve the discrimination and validity level. However, before recommending a definite change in the response format of the NEI-VFQ-25, the findings should be confirmed in additional studies among different visual impairment conditions and different demographic conditions. The NEI-VFQ-25 also needs further testing in construct validity and responsiveness. These recommendations are in line with criteria developed to assess the psychometric quality of health assessment questionnaires[38,39]. However, these proposed criteria are mostly based on evaluation of questionnaires using classical or Rasch models and need to be adapted for other item response models.

Another concern is the assessment of the magnitude and 'clinical' significance of DIF, and the decision to delete items based on this measurement property. A consequence of deleting a differentially functioning item is that the psychometric quality of the underlying construct improves. In chapters 2 and 3, the magnitude of differential item functioning for polytomous items was presented as a maximum difference in expected scores between the relevant subgroups on which DIF was tested. The magnitude of when the maximum difference in expected scores is still acceptable may depend on the questionnaire and the number of its response options, and needs further discussion. Assessing DIF remains important because previously reported 'real' differences in disability between subgroups might have been an artifact of the measurement process, i.e. they might have only reflected a difference in item interpretation by these subgroups.

Chapter 5 addresses psychometric information and studies dealing with questionnaires for age-related macular degeneration and visually impaired patients, in addition to the recent review by Finger et al. on quality of life questionnaires for age-related macular degeneration patients[8]. Eight studies were discussed with psychometric information of six vision-specific questionnaires, including the questionnaires used in this thesis (chapters 2, 3 and 4) which were filled in by visually impaired patient populations, including patients with age-related macular degeneration. When more information on the psychometric quality of vision-related quality of life questionnaires obtained from item response models becomes available, it may be necessary to review these questionnaires using criteria suitable for these models.

Finally, for low-vision rehabilitation outcomes we may need to first decide which rehabilitation goals need to be addressed and then select the items or dimensions of vision-related quality of life which one wants to evaluate. A promising approach is the Activity Inventory[20,40], which was recently translated into Dutch and has been tested in a low-vision population. The Activity Inventory was designed to measure rehabilitation needs before rehabilitation and evaluate outcome afterwards using the same questionnaire. However, global vision-related quality of life outcomes such as the VCM1, the LVQOL and the NEI-VFQ will still serve the purpose of assessing what is important to patients concerning their visual disability experienced in daily life.

Longitudinal outcomes of low-vision rehabilitation

This thesis describes the longitudinal observational outcomes of low-vision rehabilitation of 296 older patients who were referred to monodisciplinary or multidisciplinary low-vision rehabilitation services in the Netherlands. In addition to the relatively short-term effects (5-month and 1-year follow-up; **chapter 6**), it was considered important to gain insight into the long-term effects (i.e. at 4.4-year follow-up; **chapter 7**). This allowed us to understand how patients experience their quality of life, specifically with regard to vision-related issues. Most patients in the long-term study had had no contact with the rehabilitation services for a relatively long period of time.

Taking into account the lack of item invariance over time on the VCM1 and the "Reading and fine work" dimension of the LVQOL, the focus of the vision-related quality of life outcomes is on the LVQOL dimensions "Basic aspects", "Mobility", "Adjustment" and the two subdimensions "Reading small print" and "Visual (motor) skills". Table 3 shows the direction of the adjusted average group vision-related quality of life effects for the two low-vision rehabilitation types at three follow-up time points. Only the average short and long-term outcomes of the adjusted model are described (chapter 7) because they are considered more accurate than the unadjusted model (chapter 6). In addition to significant average group effects, individual effects are summarized when present in more than 10% of our study population. Furthermore, the evidence-based outcomes described in **chapter 8** are briefly discussed.

Summary of the results

For patients who went to the optometric service the direction of the long-term effect was detrimental on all LVQOL dimensions, with exception of the "Reading small print" dimension which improved. However, these results were not statistically significant. Significant detrimental individual long-term effects were seen on the "Basic aspects"

(13%), "Adjustment" (11%) and "Visual (motor) skills" (22%) dimensions, and significant long-term improvement on the "Reading small print" subdimension (19%).

For patients who went to the multidisciplinary service, significant beneficial 5-month and 1-year effects were found on "Reading small print". Significant detrimental average short-term effects were found at 1-year follow-up on the "Visual (motor) skills" subdimension. Significant detrimental long-term average effects were found on the "Basic aspects", "Mobility" and "Visual (motor) skills" dimensions. Significant detrimental individual long-term effects were found for multidisciplinary service patients on the "Basic aspects" (14%), "Mobility" (14%), "Adjustment" (10%), "Reading small print" (12%) and "Visual (motor) skills" (30%) dimensions.

Finally, gender was associated with the "Basic aspects" and "Mobility" dimensions, and education level (in years) with the "Adjustment" dimension. Men, and patients with a higher education level, were inclined to give a more positive response on those dimensions than, respectively, women and those with a lower education level. LogMAR visual acuity and health status were associated with all LVQOL (sub)dimensions. Patients with greater vision loss and a worse health status were inclined to give a more negative response.

Table 3. Direction of adjusted average group vision-related quality of life effects of two low-vision rehabilitation types

		BA	MOB	ADJ	RSP	VMS
Optometric	5 month	0	0	0	0	0
service	1 year	0	0	0	0	0
	4.4 years	0	0	0	0	0
Multidisciplinary	5 month	0	0	0	+	0
service	1 year	0	0	0	+	–
	4.4 years	–	–	0	0	–

BA: Basic aspects; MOB: Mobility; ADJ: Adjustment; RSP: Reading small print; VMS: Visual (motor) skills; 0: no significant effect; + significant improvement; – significant deterioration ($p<0.05$).

Considerations for low-vision rehabilitation services

Taking into account the detrimental or lack of effects on most vision-related quality of life dimensions has implications for both types of low-vision rehabilitation services. Especially patients with more vision loss and a worse health status were inclined to experience more visual disability during follow-up on all vision-related quality of life dimensions of the LVQOL. For example, by prescribing appropriate low-vision aids (e.g. reading aids, telescopic or filter devices) more beneficial effect on the "Basic aspects" (with the items watching television, seeing moving objects, tired eyes and glare)

might have been achieved – even though reading with low-vision aids can also be tiring. In addition, little evidence for the effectiveness of low-vision aids is available. Delivering occupational therapy in the home environment regarding light adjustment and watching television may have been necessary for more patients. The study described in chapter 8 provides evidence for improved quality of life after adjustment of lighting. However, in a study at the multidisciplinary rehabilitation service, it was found that the majority of patients overestimated their TV watching skills. Even with telescopic devices, shortening of the viewing distance or having larger TV sets, reading the subtitles remained problematic[41]. This dimension was associated with gender, with female patients experiencing more deterioration than males. Although there is no clear explanation for this result, it is an important indication that women show more disability and therefore need more attention on "Basic aspects" issues.

From the "Mobility" dimension (including items on night vision inside the house, seeing steps/curbs, depth/distance perception, getting around outdoors/crossing roads with traffic) a more positive outcome was also expected, probably mostly from multidisciplinary services. In these multidisciplinary services occupational therapists can provide mobility training for the patient, e.g. to a shopping center or family member[42]. Since gender was associated with "Mobility" with female patients showing more deterioration than males, this seems to be a subgroup that needs more attention. However, because women more often reported musculoskeletal conditions (35%) than men (12%) this may partly explain the difference in outcome or the decline on this dimension.

From optometric services it was probably less likely to find an improved "Adjustment" dimension than from multidisciplinary services. The prescription of low-vision aids, the main focus of optometric services[43], is probably not enough to enhance psychological adjustment to vision loss. A multidisciplinary approach had probably been more suitable as this can offer facilities aimed directly at the improvement of this dimension. Advice from a psychologist, social worker or an occupational therapist may have been necessary for the patients to improve their adjustment to vision loss. This dimension includes the items visiting friends and family, frustration with doing tasks and being unhappy with the situation in life. Since patients with a lower education were inclined to have lower scores on this dimension, those patients may require more attention from rehabilitation services. As a group, patients referred to multidisciplinary rehabilitation had a significantly lower level of education than patients referred to the optometric service. Frustration and feelings of unhappiness with one's life situation is a typical subject that could be discussed with a psychologist or social worker, or in group discussions with other visually impaired patients. Furthermore, checking whether the patient understands the eye condition, or if they have any recollection of the explanation given by their ophthalmologist, may

be an important intervention. Understanding the eye condition may help patients to cope with vision loss[44].

The largest effect of the optometric service could have been expected on the "Reading small print" sub-dimension, with items about problems reading small print (e.g. labels on medicine bottles, newspapers, books and mail). For multidisciplinary services significant effects were also expected, because the main rehabilitation needs often expressed by patients are problems with reading. Lack of a long-term average effect on the "Reading small print" dimension may reflect that the existing reading aids were no longer adequate. Nevertheless, almost 1 out of 5 patients who went to the optometric service showed significant improvement. Although the mean difference between distance visual acuity values did not change significantly between baseline and long-term follow-up, patient's reading acuity and its decline was not assessed. Therefore, no relation can be assumed between long-term visual disability on this dimension and a decline in distance or near acuity.

Finally, the "Visual (motor) skills" sub-dimension (with the items reading large print, reading the own handwriting, finding out the time, writing and using tools) could have improved due to specific training from occupational therapists. Patients may have needed more training to improve this dimension. Since reading is considered to be a major need for patients, other skills (e.g. writing, or finding out the time) might be given less attention by low-vision rehabilitation services.

In general, it seems that visually impaired older patients more often need to be referred to a multidisciplinary center by the optometric service or ophthalmologist, and more often need a multidisciplinary approach, than seems apparent at first. If this is achieved in future, the visual ability of patients might be enhanced on more dimensions of vision-related quality of life.

General recommendations

The most important goal of visual rehabilitation for older patients is to contribute to improvements in visual ability, to make them more independent in daily life, and more able to participate in society[40,45]. Also, considering the increasing healthcare costs and lack of manpower, the large group of older patients should be stimulated to maintain their independence and participation in society for as long as possible[45]. The results of the outcome studies show that low-vision rehabilitation services only partly succeeded in achieving this goal. Consequently, based on the results of the present study, improvements in low-vision rehabilitation services may be necessary.

The policy of low-vision rehabilitation centers is to deliver 'patient-centered' care. This means that rehabilitation is offered to patients when they ask for it themselves and is not specifically driven by the availability of care or rehabilitation 'products'. Moreover, admission to care, particularly in multidisciplinary services, is limited by

regulations imposed by government that hamper long-term follow-up of such care. This seems to be in contrast with the idea that an important reason for measuring (health-related) quality of life, also in low-vision rehabilitation, is the growing interest of governments and health insurance companies in these outcome measures as parameters for quality of care[5,6]. In current practice, patients are no longer monitored after rehabilitation ends, because rehabilitation services do not initiate new contact to enquire whether there is a need for additional rehabilitation. Furthermore, low-vision rehabilitation services may not have the capacity to monitor their (ex-)patients because the inflow of new patients is already substantial. However, our results indicate that many patients do not improve on various vision-related quality of life dimensions over a short or longer period of time, which may reflect the need for additional rehabilitation.

It is recommended that rehabilitation services introduce a regular 'need for rehabilitation check', for example once or twice every year. Rehabilitation services should at least emphasize that patients have the possibility to return to the low-vision rehabilitation center if their problem persists or worsens, or if a new need for rehabilitation arises. It is also recommended to continue the discussion on the policy of long-term patient monitoring within rehabilitation services. Monitoring may imply that when individual patients are investigated again, rehabilitation services may be able to adjust to newly encountered needs. This may not be possible or necessary for every patient, but it is conceivable for vulnerable subgroups. For rehabilitation services, a regular patient monitor will serve as a practical tool to offer the required evidence to government and insurance companies concerning the efficiency of their services, or to adjust rehabilitation programs if the efficiency is not proven. This may prove to be a cost-effective approach because patients will be able to live independently for longer periods of time. The implications for research would be that having large datasets with rehabilitation outcomes may improve our understanding of the visual disability suffered by patients and may help identify vulnerable subgroups. Outcomes should preferably be measured by research institutes independently of, but in cooperation with the rehabilitation services in order to optimize objectivity.

Subgroups appearing to need more attention and training are women on the "Basic aspects" and "Mobility" dimensions of vision-related quality of life. Another subgroup is the lower educated patients who may need more attention on "Adjustment" to vision loss, for example by explaining the eye condition again, or by individual or group sessions with a social worker or psychologist. Another subgroup to be explored is patients from non-Dutch cultural backgrounds; this group was beyond the scope of this study, but may need to be approached in a different way by rehabilitation services because of language problems and/or a lower education level among these groups. Generally, patients with more vision loss and a worse health

status need more attention. However, since there was no clear improvement on most vision-related quality of life dimensions, it was not yet clear for the low-vision rehabilitation services which needs should definitely have been addressed. The first need which is most often expressed is the need for reading and optical aids. These aids are suitable to directly improve reading skills or, more indirectly, the skills needed to improve other vision-related quality of life dimensions. This older patient group seems to need more training with, for example, these reading aids, mobility training, ADL training, etc. The problem is, however, that newly diagnosed patients (i.e. the group investigated) seem to lack an overview of what problems they will encounter in daily life when living with a visual disability. Until recently, low-vision rehabilitation centers did not have a systematic way to address these needs (it was done in a general fashion). The general intake is often included in the assessment of visual functions by the low-vision specialist or optometrists, or the assessment of needs is based on the limited information in the referral letter from the ophthalmologist, or on the assertiveness of the patient. This implies that the specific rehabilitation needs are not always clear from the start, but may emerge over time when the patient is already in the rehabilitation trajectory. It is also unclear whether patients actually receive the appropriate rehabilitation program, or whether they might be undertreated or overtreated. Too much focus on the most prominent disability, instead of the whole spectrum of problems, may be a threat to receiving proper treatment[46]. This may result in individual patients undergoing rehabilitation programs that were only partially appropriate for them[47]. In turn, this might imply that some of our patients found the road to independence and participation in society difficult to travel.

In 2006, the participating multidisciplinary rehabilitation service was interested changing their rehabilitation planning tools. They wanted to focus more directly on the patient's needs and deliver a more effective and efficient visual rehabilitation. A good example of an extensive rehabilitation planning and evaluation instrument was available, i.e. the Activity Inventory which was constructed and validated in the USA[20,40]. The Activity Inventory allows to measure specific individual rehabilitation goals, rehabilitation priorities, and specific tasks that a patient needs to be trained in. Moreover, it is demand-driven, i.e. visual rehabilitation needs are investigated from the patient's perspective. The questionnaire includes individual goals embracing the level of interest given to that goal by the patient[20,40]. The patient decides what type of rehabilitation goals are important, instead of decisions made by focusing on the availability of rehabilitation programs[48,49]. This model is highly applicable to the Dutch situation because it is designed to measure rehabilitation needs before rehabilitation, and to evaluate outcome afterwards with the same instrument. The questionnaire can be considered a more refined version of the International Classification of Functioning, Disability and Health (ICF), in the sense that also specific tasks are addressed to reach

individual goals. It serves as a practical tool to assess the important ICF domains, because the ICF does not offer a means of systematically assessing and measuring functional limitations and disabilities.

Since 2007, the department of ophthalmology of the VU University Medical Center Amsterdam has worked together with regional multidisciplinary centers to implement a Dutch Activity Inventory (D-AI). The Activity Inventory has been translated and extended. In accordance with the rehabilitation center, special attention was paid to placing the rehabilitation goals under the ICF domains at the level of Participation and Activities. The D-AI is now a computer adaptive system, it was tested in a pilot study, and then students administered the D-AI by telephone among more than 200 patients. The results of the study are not yet available, but other multidisciplinary services have shown interest in implementing the D-AI as a standard rehabilitation planning tool (it will be the only tool validated in the Netherlands).

Methodological considerations and future research

The aim of the work presented in this thesis is to describe the longitudinal effects of two low-vision rehabilitation services in terms of vision-related quality of life of older patients. Researchers in the field of low-vision have used different follow-up periods to evaluate low-vision rehabilitation in terms of vision-related quality of life in elderly populations, but have generally not exceeded 1 year post-rehabilitation[42,50]. Although loss to follow-up in a long-term study (e.g. up to 5 years of follow-up) in an older population might affect the outcome, we considered it important to know whether older patients would still experience some benefit a relatively long time after their rehabilitation had ended. Therefore, loss to follow-up was taken into account in the long-term model (chapter 7)[51,52].

Mainly to cope with missing data due to loss to follow-up, the multilevel item response model described in chapter 6 was improved by adding confounders[52]. It was assumed that the missing data could be classified as 'missing at random'. A non-response process is considered missing at random if (conditional on the observed data) missingness is independent of the unobserved measurements[51,53], i.e. vision-related quality of life. Furthermore, it is reported that generalized linear mixed models (of which the multilevel item response model is a special case) are more likely to be valid and perform better than various imputation techniques[51]. Others have also supported the use of these direct likelihood methods to deal with incomplete longitudinal data[54].

Consequently, to reduce bias, the model was adjusted for those baseline patient characteristics which were expected to be associated with the probability of a response. Simultaneously, these characteristics were informative to detect vulnerable subgroups, and some of the average group effects that were (not) found in the first

unadjusted model with two follow-up time points (chapter 6) may be partly explained by these confounders, i.e. vision loss, health status and, for some dimensions, gender and education level.

In general, there was a lack of improvement on the separate dimensions of vision-related quality of life. An explanation for the lack of effects and deterioration in vision-related quality of life might be that both visual acuity and perceived general health had deteriorated at follow-up[42,55]. Others also speculated on disease progression as a possible cause of decrease in visual ability after rehabilitation[18]. However, in our study between baseline and 4.4-year follow-up, on average the visual acuity of respondents who were still in the study at long-term follow-up did not decline.

Some limitations to the study design need to be addressed. Firstly, the focus on the rehabilitation service may not have been specific enough. It may be difficult to draw appropriate conclusions about the entire rehabilitation organization, without looking at specific programs that the patients received. For example, the fact that there was deterioration on the "Mobility" dimension does not indicate that mobility trainers are not doing a good job. It may merely indicate that rehabilitation needs were not investigated systematically for individual patients, so that the services may have been unaware of the needs of these patients. Consequently, the newly developed D-AI is a promising tool to improve the assessment of rehabilitation needs, which may result in improved visual ability of patients. However, in future it is recommended to assess specific rehabilitation programs rather than the entire rehabilitation service. When specific programs are assessed (preferably in randomized clinical trials) it will then be possible to adjust these programs as required; this may promote a more evidence-based rehabilitation system. Examples of this are the ongoing study on the effectiveness of a training protocol for use of closed-circuit television systems, or (in **chapter 8**) the studies described in the systematic review on the effects of low-vision rehabilitation. Studies on the effectiveness of low-vision aids for specific tasks are currently lacking and deserve more attention; these will enable rehabilitation workers to better advise patients as to what can be expected from the low-vision aids prescribed. This may also serve to develop improved versions of these aids.

Another limitation is that the outcome study described in this thesis was not randomized. The rationale for this was that adding a placebo or no treatment group would be unethical, because patients would have been withheld from low-vision services. This means, theoretically, that no inferences about the value of low-vision services can be drawn from this study. Waiting-list controlled studies have been proposed and have been used in a few randomized controlled studies described in chapter 8. Furthermore, it would have been preferable to randomly assign participants to either the optometric or the multidisciplinary service. Although this was not done the two groups differed only in the level of education; there were no

other significantly different characteristics between the two groups. However, other confounding variables that were not assessed might have influenced the results, such as symptoms of depression which are reported to affect rehabilitation outcomes[56]. On the other hand, cohort studies such as the observational study described in this thesis are more suitable for investigating prognostic factors than trials, because of the heterogeneous populations involved in these studies. In that case a non-randomized design is a strength of our study, whereas participants in separate arms of a randomized clinical trial are usually too homogeneous. Further research into prognostic factors of vision-related quality of life is warranted.

Finally, the multilevel item response model was investigated to describe longitudinal dependent data. The model was characterized by the graded response model[57-59] for rating scales[60]. It was useful to be able to calculate estimations of individual change directly from the model[14]. These random effects were presented as significant individual improvement or deterioration after low-vision rehabilitation. Usually, research focuses on the statistical significance of average rehabilitation outcomes of patient groups because the overall effects are important to low-vision rehabilitation services in order to determine or adjust their policy. However, even a small advantage for a low-vision rehabilitation program, when multiplied by large numbers of potential patients, could translate into a benefit for many persons[61]. Moreover, in daily practice, rehabilitation workers might be more interested in which individual patients improved or deteriorated and less in an overall rehabilitation effect. There are additional advantages in using the multilevel item response model that we investigated. All available response schemes of patients were used, and the data did not necessarily have to be complete. Also, the graded response model for rating scales is considered to be more robust than partial credit models, due to their efficient use of response categories with cumulative logits[62]. From a practical point of view, implementation of item response models for longitudinal data is currently easier for graded response models than for partial credit models[63]. We consider this model to give an adequate representation of the available data, even though we lack some information due to incompleteness of our data. In our opinion the multilevel item response model is very useful to investigate longitudinal data and individual rehabilitation effects and is, therefore, recommended for future studies.

Co-morbidity and health-related quality of life of older visually impaired patients

Insight into the prevalence of co-existing conditions is important for public health purposes, because co-morbidity increases utilization of health care, costs of medical care, and mortality. For decision-making related to medical treatment and rehabilitation, knowledge on specific co-existing conditions of individual patients is crucial. **Chapter 9** reports on the co-existing conditions suffered by visually impaired older patients and explores whether all co-existing conditions are reported when asked. The aim of this study was to present the level of agreement between the reports on co-morbidity made by the patients and recorded by their GP. **Chapter 10** investigates which co-existing conditions and patient characteristics lead to an increased vulnerability or a decline in terms of health-related quality of life in this patient group.

Summary of the results

The study in chapter 9 shows that visually impaired older patients frequently suffer from one or more co-existing conditions. Although it was not intended to prove a relationship between eye conditions and specific co-existing conditions, the study revealed that musculoskeletal (28%), diabetic (25%) and heart conditions (23%) were most often reported by visually impaired patients. Hypertension was most often reported by GPs (49%) in contrast to patients (16%). For most condition categories there was a lack of agreement between co-morbidity reports of patients and those of their GP (Table 4). The agreement differed per condition, whereby patients mostly under-reported. Poor to fair agreement was found for psychological problems, chronic skin problems, gastrointestinal conditions, chronic allergies, thyroid conditions, hypertension, cancer, musculoskeletal conditions, hearing impairments and stroke. However, for diabetes, COPD/asthma and heart conditions very good to moderate agreement was found between the patients and the GPs.

The study in chapter 10 showed that patients who reported at baseline to have diabetes, COPD/asthma, consequences of stroke, musculoskeletal conditions, cancer, gastrointestinal conditions experienced a lower quality of life (measured with the Euroqol–5 Dimensions: EQ-5D) compared to patients who did not report those conditions. In addition, patients with more vision loss experienced a lower quality of life compared to patients with less vision loss. Visual acuity, musculoskeletal conditions, COPD/asthma and stroke predicted a further decline in quality of life after 5 months. With the risk profile presented in this study it was possible to determine patients at risk for a relatively rapid decline in quality of life, in addition to patients who already experienced a low quality of life compared to, e.g., younger visually

impaired patients[64] and older adults in the general Dutch population[65]. These results (summarized in Table 4) have implications for the ophthalmic clinic and low-vision rehabilitation practice. In addition to these practical implications, methodological considerations are discussed.

Table 4. Agreement between patient and general practitioner (GP) and conditions having a detrimental impact or leading to a further decline in quality of life (QOL)

Co-existing conditions/ Patient characteristics	Agreement: Patient/GP	Effect on QOL p<0.05	Predictor of QOL decline p<0.05
Diabetes	+	−0.09	n.s.
COPD/asthma	+/−	−0.12	−0.09
Heart	+/−	n.s.	n.s.
Stroke	−	−0.16	−0.10
Hearing impairment	−	n.s.	n.s.
Musculoskeletal	−	−0.20	−0.09
Cancer	−	−0.18	n.s.
Hypertension	−/−	n.s.	n.s.
Gastrointestinal	−/−	−0.17	n.s.
Thyroid gland	−/−	n.a.	n.a.
Chronic allergies	−/−	n.a.	n.a.
Chronic skin problems	−/−	n.a.	n.a.
Psychological problems	−/−	n.a.	n.a.
LogMAR visual acuity	n.a.	−0.14	−0.07
Other patient characteristics	n.a.	n.s.	n.s.

Agreement: + (very good); +/− (moderate); − (fair); −/− (poor); n.a. not assessed; n.s. not significant;
Effect or predictor: detrimental on EQ-5D-scores (range approximately 0-1) compared to patients without the condition.

Considerations for low-vision rehabilitation services and the ophthalmic clinical practice

The results of the co-morbidity studies may help ophthalmologists and rehabilitation workers to understand that low vision and specific co-existing conditions cause a measurable extra burden, or even a rapid decline, in the quality of life in visually impaired older patients. Patients who reported to have diabetes, COPD/asthma, consequences of stroke, musculoskeletal conditions, cancer and gastrointestinal conditions, or patients with greater vision loss, experienced a lower quality of life. Moreover, visual acuity, musculoskeletal conditions, COPD/asthma and stroke predicted a further decline in quality of life after 5 months. Patients with a profile matching these variables can be considered target groups who may need to be

monitored more often. Ophthalmologists may consider referral to another sub-specialty if the patient is currently not under treatment for the condition(s) that they have reported. In addition, specialized low-vision rehabilitation programs or low-vision aids may be needed for patients with co-morbidity. Besides reading aids, these patients may need occupational therapy, specialized mobility training, more extensive training for using low-vision aids, or help from a social worker to adapt to their visual disability, i.e. a multidisciplinary approach.

With a risk profile as presented in this study, a rehabilitation intervention or a specific referral to another sub-specialty may be of benefit for the general health and vision-related quality of life of the patient. When taking these results into account, the involvement of ophthalmologists and low-vision rehabilitation services may serve to improve a patient's general health. However, care providers should be aware that patients often under-report co-morbidity. Although patients are an attractive source of information regarding their co-morbidity, it is recommended that providers pay special attention to co-morbidity in visually impaired older adults when taking the patient's history. Using a pre-structured format may help, or providers may ask these older patients about the conditions that cause an extra burden or lead to a rapid decline in their quality of life.

A more complete view on the patient's health status will then become available, which may influence health and rehabilitation outcomes, the rehabilitation program for patients, or medical decisions. With the increasing use of electronic patient records in the Netherlands and other countries, it should become easier to check co-morbidity (including medication use) which should contribute to the total picture of co-morbidity among patients and to the safety of medical decision-making.

Methodological considerations and future research

Although our results should be confirmed in a future study using pre-structured co-morbidity questionnaires, the present work has shown that visually impaired older patients with specific co-existing conditions and low vision experienced a lower quality of life, and were at higher risk of a rapid decline in quality of life. Moreover, our results were largely in line with those from an earlier population-based Dutch study[66]. In the co-morbidity studies described in this thesis, the reliability of co-morbidity assessment should be discussed and its implications still need to be explored. First, a possible explanation for the lack of agreement is that co-morbidity was assessed in two different ways. Open-ended questions, which were used, are known to result in lower level of reporting than more specific methods of questioning[67]. As expected, the open-ended nature of the question probably restricted patients from writing down all the conditions they suffered from. This may have contributed to the lower number of self-reported co-existing conditions compared to the GP reports. However,

the open-ended question method is perceived to be comparable to the way co-morbidity is usually addressed in a clinical setting[67]. If patients and GPs had been given a comparable list of co-existing conditions, this might have provided more similar results.

Second, in our study it was observed that between baseline and follow-up the reports on co-morbidity were not stable. One reason for this was loss to follow-up, and the other was that the patients did not continue to report the co-existing conditions that they had reported at baseline. Moreover, some patients reported co-existing conditions for the first time at the follow-up measurement. It is uncertain whether these changes in self-reports reflect a true change over time; perhaps patients simply failed to report these conditions at baseline, or were unaware of the condition, or symptoms were absent, or there were recollection problems, or perhaps patients considered it superfluous to report their (chronic) co-existing condition(s) at the second measurement. In contrast, Klabunde et al. showed that patients were generally able to provide reliable reports of their co-existing conditions over time[68].

In general, asking for co-morbidity in an open-ended style may have implications for research in the fields of low vision rehabilitation, or epidemiological studies. Open-ended questions are generally considered suboptimal for assessing the prevalence of co-existing conditions because in that case mainly the serious conditions are reported[69]. Many researchers correct their outcomes for, or predict outcomes from, variables such as the number of co-existing conditions, the presence of co-morbidity, or they try to find associations between specific co-existing conditions and eye conditions. The results show that asking with an open-ended question does not result in a complete view of the co-morbidity of visually impaired older patients. Fortunately, other studies do use existing co-morbidity lists, medical records or records from insurance companies, which seem to provide a more complete view of the patient's co-morbidity and higher agreement for the majority of conditions[70,71]. Therefore, for research purposes, if medical records are not available or are incomplete, it is recommended to ask patients for co-morbidity with a pre-structured questionnaire in order to avoid this type of omission; these questionnaires are easier to complete by older patients because they depend less on their recollection ability. Other questionnaires are available which cover the severity of the co-existing condition and whether patients are currently treated for it[72]. In addition, it may be too time consuming and too costly (due to the personnel involved) to use the medical records of patients. Although medical records are considered the best way to collect co-morbidity information[73], they may be incomplete[74]. The co-morbidity studies in this thesis did not include a thorough investigation of the nature of open-ended questions. More research is needed to establish the reliability of open versus closed-ended questions administered by patients. In a recent study, however, it was

reported that setting and registry characteristics affect the prevalence and nature of multi-morbidity in older adults[75]; these authors recommended to provide information at least about the setting, the conditions, the data collection method, and the time frame in which conditions were measured, when reporting about the size and nature of multi-morbidity.

Finally, an omission in the current study was psychiatric co-morbidity; recent studies have indicated that approximately one-third of older adults who are visually impaired suffer from (symptoms of) depression[76,77]. In the list of co-existing conditions which had to be administered by the GP, a psychiatric conditions category was not included; nevertheless, some patients still reported such problems. Other studies reported that psychiatric morbidity is not well recognized in general practice[77,78], particularly in patients with somatic conditions[79]. Therefore, research into psychiatric morbidity seems indicated.

In 2009 a study will start at the VU University Medical Center, in cooperation with regional low-vision rehabilitation centers, with the aim to screen visually impaired older patients for depression and to improve referral to specialized care.

General conclusion

One of the main themes of this thesis is the assessment of the psychometric quality of vision-related quality of life questionnaires in an older visually impaired population. The VCM1, the LVQOL and the NEI-VFQ serve the purpose of assessing what is important to patients concerning visual disability experienced in daily life. Instead of classical test theory, methods from item response theory were conducted on the Dutch versions of these questionnaires. Overall, the studies show that the questionnaires have acceptable psychometric quality and can be used in outcome or screening studies. However, some areas of psychometric evaluation still need to be addressed and some adaptations to the questionnaires may be required.

Another central theme was to measure the longitudinal outcomes of low-vision rehabilitation in optometric and multidisciplinary services. Measurement of the longitudinal outcomes was successfully conducted in a multilevel item response model, which was suitable for investigating individual effects in addition to average group effects. Furthermore, it has been argued that these models are more likely to be valid when handling missing values and are therefore recommended. Moreover, the results of the outcome studies show that low-vision rehabilitation services only partly succeeded in achieving the goal of improving vision-related quality of life, especially when patients had no contact with these services for a long time. Consequently, based on the results of the present study, improvements in low-vision rehabilitation services may be necessary. Focus on systematic assessment of rehabilitation needs and longitudinal monitoring of vulnerable subgroups of patients seems warranted. Evidence for specific rehabilitation programs and low-vision aids is a necessary focus for research in the near future.

A third important aim was to investigate co-morbidity of older visually impaired patients and its relation to health-related quality of life. Patients reporting specific conditions such as diabetes, cancer or gastrointestinal conditions experienced a lower quality of life. In addition, more vision loss, musculoskeletal conditions, COPD/asthma and stroke predicted a relatively rapid decline in quality of life 5 months after baseline. A rehabilitation intervention or a referral to another sub-specialty may be beneficial for the patient. However, care providers should be aware that patients often under-report co-morbidity. Although patients are an attractive source of information for research or clinical purposes, a pre-structured format should be used to assess co-morbidity. This will provide a more complete view of the patient's health status, which may have a beneficial effect on medical decisions and consequently the patient's general health. Finally, knowledge of the patient's co-morbidity and general health may influence the content of a rehabilitation program. This is expected to be beneficial for rehabilitation outcomes of individual visually impaired older patients.

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CHAPTER 12

Nederlandse samenvatting (Dutch summary)

Introductie

Hieronder volgt een Nederlandse samenvatting van het proefschrift getiteld: *"Longitudinale analyse van visus-gerelateerde kwaliteit van leven van de oudere patiënt"*.

Visuele beperkingen, d.w.z. slechtziendheid en blindheid, komen in het Westen steeds vaker voor[1]. De prevalentie van visuele beperkingen stijgt vooral snel na het 65e jaar en van blindheid na het 85e jaar[1,2]. In Nederland wordt geschat dat met name door de vergrijzing het aantal volwassenen met een visuele beperking met 18.7% zal toenemen van circa 298.000 personen in 2005 tot 354.000 personen in 2020[3]. In Nederland en andere Westerse landen is de belangrijkste oorzaak van visuele beperkingen macula degeneratie (slijtage van het netvlies), cataract (staar; vertroebeling van de lens), diabetische retinopathie (bloedingen/verstoppingen van vaatjes in het netvlies) en glaucoom (oogzenuw die door een chronisch te hoge druk geleidelijk in functie achteruitgaat)[1-3]. Voor mensen met een visuele beperking is revalidatie een belangrijke behandelmogelijkheid[4].

Vooral wanneer genezing niet meer kan worden verwacht, zoals bij visueel beperkte patiënten met chronische oogaandoeningen, is het belangrijk dat bij elke keuze voor behandeling de kwaliteit van leven van de patiënt in acht wordt genomen. Kwaliteit van leven omvat de domeinen fysiek, psychisch en sociaal functioneren. Naast algemene kwaliteit van leven wordt het perspectief van de patiënt op zijn visus-gerelateerde kwaliteit van leven steeds vaker als een belangrijke weergave gezien van het visueel functioneren voor en na behandeling of revalidatie[5,6].
In dit proefschrift zijn drie thema's onderzocht:

1. De psychometrische kwaliteit van visus-gerelateerde kwaliteit van leven vragenlijsten;
2. De korte- en langetermijn uitkomsten van revalidatie van ernstig slechtziende ouderen;
3. Comorbiditeit onder ernstig slechtziende ouderen en de relatie met gezondheids-gerelateerde kwaliteit van leven.

Psychometrische kwaliteit van visus-gerelateerde kwaliteit van leven vragenlijsten

In de afgelopen jaren zijn er veel visus-gerelateerde kwaliteit van leven vragenlijsten ontwikkeld[5,7,8]. Eén van de hoofdthema's in dit proefschrift is het evalueren van de psychometrische kwaliteit van drie van deze vragenlijsten onder slechtziende (oudere) volwassen patiënten; in **hoofdstuk 2** de Vision-related quality of life Core Measure (VCM1), in **hoofdstuk 3** the Low Vision Quality Of Life questionnaire (LVQOL)

en in **hoofdstuk 4** the National Eye Institute - Visual Function Questionnaire (NEI-VFQ-25). Deze vragenlijsten zijn bedoeld om te kunnen beoordelen hoe patiënten hun visuele beperking ervaren. Om de vragenlijsten goed te kunnen evalueren zijn statistische modellen uit de item-responstheorie gebruikt. In item-responstheorie wordt aangenomen dat items op een vragenlijst een 'onderliggend' of 'latent' construct meten[9]. Het concept visus-gerelateerde kwaliteit van leven wordt gezien als zo'n onderliggend construct, omdat het niet direct kan worden gemeten, zoals iemands lengte of gewicht. Er zijn een aantal belangrijke voordelen voor het gebruik van item-responstheorie boven de meer gangbare klassieke testtheorie, bijvoorbeeld het gemakkelijker kunnen waarborgen van constructvaliditeit, want zodra het item-responsmodel de gegevens accuraat weergeeft ('fit'), is dat empirisch bewijs dat de geobserveerde respons op de vragenlijst verklaard wordt door de onderliggende structuur. Item-responsmodellen kunnen makkelijker ontbrekende gegevens aan en houden gemakkelijker rekening met meetfouten. Ook heeft een item-responsmodel minder problemen met plafond en vloereffecten: kwaliteit van leven gegevens laten vaak een scheve verdeling zien, maar in een item-responsmodel is men vrij om de verdeling van het onderliggende construct te specificeren, zolang men er vanuit kan gaan dat de aannamen van het model correct zijn[10]. De uitkomsten van de studies naar de drie vragenlijsten lieten zien dat deze over het algemeen acceptabele psychometrische kwaliteit bevatten. De items van de VCM1 en de LVQOL konden accuraat worden gefit in het graded response model. Echter, sommige psychometrische aspecten zijn nog niet geëvalueerd en er zijn soms nog wat aanpassingen nodig aan de vragenlijsten (bijvoorbeeld verwijderen en/of toevoegen van items). Voor de VCM1 wordt bijvoorbeeld aangeraden om één manier van afname te gebruiken: mondeling dan wel schriftelijk. Verder interpreteerden patiënten een aantal vragen als meer problematisch dan personen met een vergelijkbare visuele beperking (gemeten met de VCM1) uit de algemene bevolking. De mogelijkheden van het gebruik van de VCM1 als screeningsinstrument moeten verder worden onderzocht. De LVQOL die na dit onderzoek uit 21 items bestaat, is geschikt om te gebruiken in heterogene populaties van slechtziende ouderen. De vragenlijst presenteerde vrijwel geen differentieel item functioneren (DIF), wat betekent dat de itemrespons van personen wordt bepaald door het beoogde onderliggende construct en niet door bepaalde kenmerken van deze personen. Echter, op dit moment kan niet worden aangenomen dat de LVQOL-dimensie "Lezen en fijn werk" vrij is van DIF over tijd. Verder onderzoek naar deze dimensie, alsmede naar bevestiging van de factorstructuur, wordt aangeraden. Dit laatste geldt ook voor de NEI-VFQ-25. Tenslotte wordt in **hoofdstuk 5** aanvullende psychometrische informatie van een aantal vragenlijsten gepresenteerd. Dit hoofdstuk is geschreven naar aanleiding van een overzichtsartikel dat onlangs verscheen over vragenlijsten voor patiënten met macula degeneratie[8]. In de toekomst

is het belangrijk om een systematisch overzicht te verkrijgen van de psychometrische kwaliteit van visus-gerelateerde kwaliteit van leven vragenlijsten aan de hand van item-responsmodellen.

Korte- en langetermijn uitkomsten van revalidatie van ernstig slechtziende ouderen

Vervolgens zijn de longitudinale uitkomsten beschreven van oudere slechtziende patiënten (N=296; gemiddelde leeftijd op baseline: 78 jaar) die werden verwezen naar mono-disciplinaire revalidatie door een optometrist of naar multi-disciplinaire revalidatie door een regionaal centrum. Naast de relatief kortetermijn effecten (5 maanden en 1 jaar; **hoofdstuk 6**), werd het van belang geacht om inzicht te krijgen in de langetermijn effecten (4 tot 5 jaar; **hoofdstuk 7**) van revalidatie. Dit gaf ons de mogelijkheid om te observeren hoe patiënten hun kwaliteit van leven ervaren wanneer zij meestal al lang uit het zicht van revalidatie waren. De baseline meting vond plaats tussen juli 2000 en januari 2003. Om de langetermijn effecten te onderzoeken is een laatste meting uitgevoerd tussen juli 2005 en januari 2007. In deze hoofdstukken is een meerniveau item-responsmodel onderzocht om de longitudinale uitkomsten van revalidatie adequaat te kunnen beschrijven. Met dit model is het mogelijk om naast gemiddelde uitkomsten voor beide revalidatie typen, individuele uitkomsten te beschrijven. Het wordt aangeraden deze typen modellen te gebruiken, omdat zij meer valide worden geacht in de omgang met ontbrekende gegevens, dan de meer gangbare longitudinale modellen, bijvoorbeeld ANOVA. De uitkomsten laten zien dat de revalidatie centra slechts gedeeltelijk zijn geslaagd in het verbeteren van visus-gerelateerde kwaliteit van leven, vooral op lange termijn. Daarom lijken verbeteringen in de revalidatie organisaties op zijn plaats. Te denken valt aan het systematisch inventariseren van revalidatiebehoeften vanuit het perspectief van de patiënt om revalidatieprogramma's directer te laten aansluiten bij deze individuele behoeften. Ook het langdurig monitoren van patiënten is van belang, zeker onder kwetsbare groepen slechtziende ouderen. Uit het onderzoek blijkt immers dat een aantal zich niet goed redt op korte en lange termijn. Wetenschappelijk bewijs voor specifieke revalidatieprogramma's is waar onderzoek en praktijk zich in de komende jaren op zal moeten richten. Voorbeelden hiervan worden aangedragen in **hoofdstuk 8**, waar een samenvatting wordt gepresenteerd van een systematische review van gerandomiseerde gecontroleerde trials naar revalidatie uitkomsten in termen van kwaliteit van leven.

Comorbiditeit en kwaliteit van leven van slechtziende ouderen

Naast de oogaandoeningen die slechtziendheid en blindheid veroorzaken zijn er allerlei andere (chronische) aandoeningen waar oudere patiënten in toenemende mate aan lijden. Comorbiditeit wordt gezien als een ernstige bedreiging van de kwaliteit van leven[11,12]. Inzicht in combinaties van aandoeningen die maken dat patiënten een slechtere kwaliteit van leven ervaren is belangrijk voor de individuele zorg aan de patiënt, maar ook voor de gezondheidszorg in het algemeen[12]. Het is echter bekend dat oudere patiënten moeite kunnen hebben zich te herinneren aan welke specifieke aandoeningen zij lijden, wanneer hen dit in een klinische of onderzoekssetting wordt gevraagd. In Nederland heeft de huisarts meestal een compleet overzicht van de medische status van patiënten. Daarom zijn in het onderzoek dat beschreven staat in **hoofdstuk 9** de comorbiditeitsgegevens die werden gerapporteerd door de patiënt vergeleken met die van de huisarts. Vervolgens wordt in **hoofdstuk 10** onderzocht welke specifieke aandoeningen en patiëntkenmerken volgens patiënten tot een slechtere gezondheidsgerelateerde kwaliteit van leven of een achteruitgang van kwaliteit van leven hebben geleid. Kwaliteit van leven werd gemeten met de EuroQol - 5 Dimensies (EQ-5D). Uit het onderzoek blijkt dat patiënten die o.a. de aandoeningen diabetes, kanker of maagdarm aandoeningen rapporteren, een slechtere kwaliteit van leven ervaren dan degenen die deze aandoeningen niet rapporteerden. Patiënten die meer visusverlies, aandoeningen van het bewegingsapparaat, COPD/astma of een cerebrovasculaire aandoening (beroerte) rapporteren, ervaren na vijf maanden een achteruitgang in hun kwaliteit van leven. Revalidatie of een verwijzing naar een ander medisch specialisme is op zijn plaats voor deze patiënten. Het is echter van belang dat men zich realiseert dat patiënten comorbiditeit vaak onderrapporteren en dat de overeenstemming met huisartsenrapportages laag is. Dit is een belangrijke uitkomst van het vergelijkend onderzoek tussen patiënt en huisarts. De patiënt is zelf een aantrekkelijke bron van informatie; er wordt echter aangeraden om een voorgestructureerde lijst te gebruiken om alle comorbide aandoeningen te kunnen vaststellen. Op die manier wordt een vollediger overzicht beschikbaar van de gezondheidsstatus van de patiënt, wat zijn weerslag heeft op medische beslissingen en daarmee de gezondheid van individuele patiënten. Tenslotte zal kennis van comorbiditeit en algemene gezondheid van de slechtziende patiënten ertoe kunnen leiden dat men beter rekening kan houden met de inhoud van het op het individu toegespitste revalidatieprogramma. Verwacht wordt dat dit een positieve invloed zal hebben op de uitkomsten van revalidatie van individuele slechtziende oudere patiënten.

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